An Inquiry into the Education and School Experiences of Siblings of Seriously Ill Children

by

Jessica Ann Schaeffer Moyes

A thesis submitted in partial fulfillment of the requirements for
the degree of

Master of Education

in

Educational Administration and Leadership

Department of Educational Policy Studies
University of Alberta

© Jessica Ann Schaeffer Moyes, 2015

ABSTRACT

The education and school experiences of siblings of seriously ill children are greatly affected when the family of an ill child is required to travel for life saving treatment. This study inquired into the narratives of the children as temporary and uniquely challenged students in Alberta to investigate the research puzzle of how school age siblings of seriously ill children perceive and make sense of their school and education experiences when a child in the family becomes seriously ill and must travel for medical care. Conversations with the students allowed one to locate their perceptions and meanings at the centre of research and within the larger conversation about education policies and practices. Utilizing a children's rights lens, the research considered the viewpoints of the students regarding their respective educational journeys and subsequent needs against the considerations and resources actually made available. Together, the stated educational requirements, changing priorities and the demands on the child allowed for the research to provide a comprehensive collection of policy, practice and research recommendations to be put forth for consideration. Consistent among them, however, is the need to involve the child in the conversations directly affecting them.

DEDICATION

This work is dedicated to my mother and dearest friend. Without your sharing of one your favorite books with me as a child and your tireless support throughout the years as I chased dream after dream, I never would have found the path to this life.

I also dedicate this study to my five co-authors and their families. Your generosity and willingness to share treasured memories will forever remain with me. I am honoured to have been trusted with your stories. I thank you, all, for your support of my journey and your rich contribution to it.

ACKNOWLEDGEMENTS

Thank you to my supervisor, Dr. Lynette Shultz, for your care and patience of my process. I’m grateful for your generous and consistent support of my passion for these students.

Thank you to my committee, Dr. Jean D. Clandinin and Dr. Joe da Costa, for your generous contribution to my study.

Thank you to my peers for sharing your process with me as I navigated my own. You each brought an unimaginable depth to my work and this experience.

Finally, thank you to my participants. Every day your stories reminded me of why I began this journey. I have truly enjoyed living amongst them.

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION TO THE RESEARCH

For children, school is the most important component of life outside of the family. The average child spends the majority of their days at school learning important academic and social lessons. For this reason, one's educative journey and peer relationships within and outside of the school landscape may have lasting effects on a student's ultimate academic outcomes and engagements. In the current study, I investigate one circumstance which can quickly disrupt a student's education and school journey; the serious illness of a child. The illness of a child affects the entire family but often discounted in academic research and institutional policies are the healthy children in the family. This group of learners bear very distinct marks as the result of being the sibling of a seriously ill child who is required to travel for medical care.

Believing all children possess unique and important knowledge regarding their education, this research attempts to make visible the list of realities and complexities which threaten to disrupt one's relationship with education and/or present opportunities for personal and familial growth. To reveal these dynamics, I employ a narrative inquiry methodology and a children's rights framework for analysis. Alongside the five participants, we engaged in the process of recalling our experiences, sharing them with one another and consequently reliving, creating and realizing the meanings we attach to them. As we explored our respective narratives, we attempted to address the following research puzzle: how do school age siblings of seriously ill children perceive and make sense of their school and education experiences when a child in the family becomes seriously ill and must travel for medical care? To understand the research puzzle more fully, I inquired into a number of supportive questions such as: how can the perspectives of these students, as presented through their narrative, be understood? What is the importance of the child's voice in the larger educational landscape? How is an equitable and appropriate education best delivered to these uniquely challenged students when their learning occurs outside of formal educative spaces?

I begin the conversation in the following paragraphs by first introducing a temporary residence relied on by all of the families in this study (The House). I describe the setting as both residence and learning resource. As noted, this location was the site in which I met the participants and where they received the majority of their educative support while away from one's home community. Following, I present the impetus for the current study which arose while working at the House. Finally, I iterate the significance of the study to the participants, their families, to discourse around children's rights and to education policy and pedagogy broadly.

The House: Home and Learning Place

Referred to as "The House" by residents and staff, the nonprofit organization provides a home away from home to families with a seriously ill child when the child must reside in the hospital or require treatment in a nearby hospital.[1] Supported through private and public funding sources, the organization intends to help maintain the quality of life for out-of-town families by offering an affordable means of keeping families together during times of great stress through supportive programming and services. A large part of supporting resident families is the House's ability to ensure a family's peripheral burdens are eased while displaced. This is accomplished by making available as many resources and tools to families either free or at a drastically reduced cost that each family would likely have access to if they were home living in their permanent residence. Families enjoy the use of free internet, laundry, kitchen and parking facilities. All school age residents are able to receive educational instruction while residing at the House. To elaborate on the House, the following two sections describe the two areas mentioned that bear most significance to the goal of the current study: the residence and education program.

The Residence

The House is part of a global charitable organization. It is one of fourteen such facilities in Canada and one of 322 in 52 countries. Each facility operates under the same name and are guided by similar codes of conduct. The House particular to the current research is home to thirty two families at one time and serves approximately a thousand families annually from around Canada and the world. This House sees very few days with a room unoccupied. The collective time over a course

---

[1] Note: throughout the research, information about the House comes from websites and public documents. This information has been removed to protect the anonymity of participants.

of a year is less than two weeks and is largely due to the time it takes House staff to clean family suites and the hours between a family checking out of the House and the next family checking in to stay.

To qualify for temporary residency at the House, a family must permanently live at least 45 kilometers outside of city limits. This is the only tenet to qualify to stay at the House. Income, anticipated duration of stay and condition of the sick child are not seen as means of discrimination or grounds for priority when considering the stay eligibility of a family.

The Education Program

The Education Program operated within the House aims to supplement the academic endeavors of the resident children while providing a sense of normalcy to all school-age people and their families during a very difficult and unpredictable time. It also attempts to provide a safe place for children to talk about their emotions and make social connections with other children going through similar challenging circumstances. To this point, the participants in the current study each affirm knowledge of one another's struggles and victories through the connections made available at the House created an invaluable bond between them.

To facilitate learning at the House, the organization employs one Alberta certified teacher. Additionally, as many as two volunteers at one time from the community share the responsibility of providing one-on-one educational support to the children from thirty two families at a time. Each weekday, instruction is offered similarly timed according to what students are accustomed to; lessons begin at 9 am and run until 12 pm. Following formal instruction, social activities are organized for the afternoon hours providing the children with an opportunity to engage creatively with one's fellow House and classmates.

At the time of data collection in 2013, the classroom was a small space tripling as a craft storage room and recreation/activity site. The room could accommodate up to twelve students at one time comfortably. Technologically and in terms of resources, the classroom had five laptop computers, five tablets and one Smart Board. The House's library was limited to a small supply of fictional, reference and Alberta curricular text books. Non-fiction books were donated to the House by individuals from the community as well.

Lesson plans were created for each child upon entry into the program and were designed in a variety of ways depending on the circumstances of the student. Normally, as reinforced by the students, individuals in grades two and higher brought homework and assignments with them as given by one's teacher at their permanent school. Students in grade one typically did not bring homework but rather received grade appropriate instruction based on Alberta curriculum from the resident teacher. If the student's stay was predicted to span an extended period of time, the teacher coordinated with the student's teacher(s) in the school of permanent enrollment so as to communicate attendance and participation as well as to submit assignments on the student's behalf. It should be noted, however, that although these efforts were consistently made by the teacher to specify attendance and participation in the Education Program, whether or not the teacher in the child's home school chose to count the student's presence was entirely dependent on each teacher, school and larger governing bodies overseeing policy and practice.

Despite consistent reporting from the House teacher to each student's home school and educators, great variance persisted as to what aspects reported were considered legitimate and counted toward a student's academic record. This subjectivity posed a fundamental complication and contradiction to the efforts of the Education Program, teacher and students. Recognizing these discrepancies that existed between cities and provinces, the House determined the goal of attaining official accreditation under the local Public School Board (PSB). As a first step in the process, in 2012, I collaborated with the program teacher and Executive Director of the charitable organization to define the program parameters and mission in hopes of presenting our argument to the PSB that school age people living at the House are challenged academically similar to their ill siblings. The ultimate goal was gaining consideration for envelopment of the facility's essential Education Program into the *Specialized Programs* division of the PSB. The PSB defines specialized programming as a division of PSB intended to

> support students unable to complete their studies at school due to medical conditions, emotional or behavioural challenges, or young offender status. Delivered in partnership with community agencies, government or hospitals, students are assessed and placed into an appropriate program. Students receive support in building academic, social and independent living skills (http://www.epsb.ca/programs/specializedprograms/).

This alignment would see the education of school-age students residing temporarily at the House presided over by the same administrative team overseeing the schools operating within the area hospitals treating in-patients of school-age. To include the House students would realize the need to authenticate the proposed Education Program and provide regulated educational instruction, supporting all of the temporary resident students attending the House Education Program. After much development of the Program, the meeting between the House and PSB occurred in 2012 with disappointing results. The outcomes of that conversation and implications are presented fully in coming chapters.

Participant – Inquirer Relationship

From 2010 to 2012, I was employed by the House. My official role was to raise a portion of the approximate $2.4 million in operational funds required to ensure the future of the facility each year. The role came to include developing the House Education Program. Unofficially, my role expanded to a volunteer role contributing to various children's programming and eventually grew to include the titles of friend and advocate to the resident families.

In the first year of my employment, I remained at a comfortable distance from the families at the House. I saw them in our shared spaces at points throughout the workday but I was focused on performing the formal tasks of my job. I engaged in light conversation with residents but I did not invest in their lives. While I'm not entirely clear why I maintained a distance and limited interaction with families, exploration of my memories of that time through the narrative inquiry process reminded me of the upset I felt watching families struggle each day and with my personal feelings of helplessness. It was easier for me to remain safe in my office seemingly. To elaborate and clarify, families staying at the House all experience extreme emotional highs and lows as they receive news of a child's health. Parents and siblings return to the residence daily to share stories of medical success, diagnosis or lack thereof. It is the unwritten expectation of employees who work within the home of the families to learn how to process the information families share and to provide comfort, encouragement and emotional support. Emotions are raw and impactful and I struggled to comprehend the difficult realities of these families or how I could possibly support them meaningfully.

Over the course of two years working at the House, I came to find my way as a supportive friend to hundreds of families. I redefined my role, shifting the balance from focusing on the formal tasks of my job to include making significant efforts to socialize with and listen to the stories of the families. I also focused my attention on the resident sibling children. As I invested in the lives of the many, they reciprocated with a mutual investment and interest in my life.

Within our newly foraged relationships, I learned of the extensive difficulties facing all of the members of the family. I became aware of the uncontrollable familial circumstances and local policy restrictions which served to challenge the quality and continuity of the education received by the sibling children. As such, in 2012, I determined the focus of my research after specific events and conversations transpired between myself, resident families and administrative individuals representing the Public School Board.

Origin of the Research

As hinted at previously, the initial motivation for this study was derived from several factors: a demonstrated need to investigate the educative disconnection of the well children, and due to the lack of their inclusion by formal governing bodies into education systems. Further, as I engaged in the research, I added to this list the fact that academic research interrogating the educational plights of siblings of seriously ill children is terribly limited and the perspectives of children, those whose lives are being discussed, are rarely collected and made visible in academic resources.

In mentioning a demonstrated need for this research, I drew upon my recollection of the first example which made evident the necessity to perform research on this topic. In 2012, on a typical day at work, my colleagues and I sat in the kitchen eating lunch in the company of several families. Without warning, a medical emergency occurred calling study participant, Tom, and his family into action. Tom's sister was suffering a cardiac arrest. To those standing out of the way, it was clear each member of the family had their roles: Dad resuscitated the little girl, Mom called 9-1-1 and Tom raced to the family's suite to retrieve the oxygen tank. Watching them in action unfortunately confirmed that the family had performed this synchronized dance too many times before.

When Tom returned with the oxygen tank to where his father was working to save his sister, panic worsened. Tom brought down the wrong tank. It was empty and his sister now had just minutes to be revived. Tom's Mom raced up to the room to get the tank of oxygen as quickly as possible. If Tom's reaction in that moment of shock was any indication of how he felt, however, he believed the damage was already done. In his mind, Tom may have just sealed his sister's fate. I watched as this twelve year old boy responded emotionally and physically to the situation. When emergency teams arrived to take his sister to the hospital, Tom walked out of the building in his socked feet alone. A short time after, he returned and was surprisingly willing to speak to my colleague and me about the incident. Displaying feelings of distress and anguish, he shared his frustration for the situation and anger towards himself for having failed his sister. To Tom, part of his job in life was to keep his sister alive – this story and his elaboration is discussed further in Chapter 4.

That afternoon I thought deeply about Tom's perception of his responsibilities. As the sibling of a seriously ill child, his priority was the survival of his sister at any cost. I understood the circumstances that guide his intention but I couldn't help but wonder where typical priorities and desires of a twelve year-old's life, such as education and play, sat on the spectrum. What essential academic and social lessons were being missed? I narrowly focused on what was lacking in his formal education or what was taken from this student due to the familial circumstances. Interestingly, my ideals were challenged by the student participant's own perceptions in this study broadening the conversation and research puzzle beyond anticipation.

The secondary point of origin driving this research came from the outcome of efforts associated with trying to establish an accredited school within the House under the supervision of the PSB. As conceptualized in the design of the proposed program, the legitimization of the Education Program as a school would see all temporary resident students able to enroll, allowing their attendance to be formally counted. Students would also receive standardized lessons concurrent with Alberta curriculum. The school could provide additional provisions based on the unique circumstances of the children. This would include resident teachers(s) establishing a communication plan, ensuring consistent contact with the child's teacher(s) in their home school and thus assisting in the child's re-entry into their home school. An additional consideration of this argument for the necessity of the school is the fact that students attending the program would be able to learn in a controlled environment. This is of particular importance when a sick child with a weakened immune system is living with their family in the House and is threatened by the presence of the most common virus.

Upon the formal establishment of the Education Program, the Executive Director of the House, the teacher and I met with a variety of education policy and advisory leaders in the area. We gained considerable guidance and encouragement for the evolution of the program into an accredited school. We then met with Assistant Superintendent for the PSB. After stating our case for inclusion under the PSB umbrella of *Special Programs and Schools*, Assistant Superintendent acknowledged the need to provide instruction to the resident students, stating they do in fact hover in a grey area between institutions and in effect, receive a subpar education (Personal Correspondence, March 2012). Despite this acknowledgement, we were informed research would need to be performed to determine if a partnership or full inclusion into the PSB could be possible (Personal Correspondence, March 2012). Ultimately, the PSB ruled against our request stating they would not be able to formally support the students residing at the House based on the following facts: policy is in place to allow all temporary residents to attend a public school, and the student's home school in which they are enrolled carries the funding assigned to each student which means responsibility and learning resources sits within their jurisdiction.

Obviously this determination was very disappointing. At first thought, the Assistant Superintendent and PSB appeared to announce a pragmatic decision based on policy and precedent. I, however, was left to consider the marginalization of the students as 'one of them' and where that left the children in the matter of their relationship with education. Where did the rights and best interests of the child as outlined in the Declaration of the Rights of the Child (1959), United Nations Convention on the Rights of the Child (1989) and Alberta Schools Act (1988) fall into the decision? By not acknowledging the full rights of children, I recognize they are treated as 'less than' against their more stable peers. Additionally, if this would be the end of the conversation between the House and PSB, I was determined to ask; how these students can be served differently or better than they currently are? Taking this conversation further and considering the perspectives and voices of the children, the rights of the child to an equitable and appropriate education are discussed in depth in Chapter 6 but weighed heavily in considering the potential impact of this study.

The final influences to the current study are drawn from the general void of childhood humanity and voice reflected in research. When I began the literature review process, I was struck by the lack of academic attention paid to the siblings of sick children. In the course of the last eighty years, while attention has been given to families of sick children, scholars have primarily directed their studies on the effects of illness on the sick child or whole family unit with very little emphasis on the well children. Additionally left out of academic consideration is the fact that most families are required to travel for medical treatment when a child is diagnosed with serious illness. Travel is necessitated by the fact that, at least within Canada, centers of medical excellence are spread widely between institutions and provinces. For example, children around the world travel to The Hospital for Sick Children (SickKids) in Toronto, Ontario for cancer treatment because the medical teams at SickKids are the leaders in oncology research and treatment in the world. Similarly, researchers and practitioners in Edmonton, Alberta lead the pack in both research and treatment of childhood heart conditions. Even less so considered are the merits of listening to and including the narratives of children in the research so as to deepen our understanding of their experiences.

Taken together, the vast collective of inspirations for this study speak to its significance on all levels; my personal curiosity, in consideration of the children in question and to further our understandings of how these individuals come to perceive, and believe through experience.

Personal Significances of the Study

This study seeks to bring the perceptions and voices of the school-age sibling(s) of seriously ill children required to leave the home community to the fore in part because it has not be explicitly done to date. By requesting the participation of the children alone and presenting their views, the study lends itself to affirm to all parties that each child's perspectives are important, specialized and do not require adult validation. This is significant, as suggested by Tom's father, in supporting the student's ability to process the difficult events and subsequent outcomes. In an email from Tom's father following my conversations with his son, he stated,

> *We think this is therapeutic in terms of (Tom's) acceptance of the path we've been on, by sharing with you. He has internalized too much of what happened – especially the cardiac arrests… you are probably the first person he really shared with* (Personal Correspondence, May 30, 2013).

Tom's father's gratitude was echoed by other parents. The dominant belief was that by engaging the children and articulating the need to make their struggles and success visible, the students were able to recognize an important role in life as catalyst for change, able to ignite the conversation and hopefully affect the consideration given to others similarly challenged. Adding their insights to the current study helped them locate yet more identities of inquirer and specialist. I also believe that telling their stories and making sense of the winding road that lead them to where they are, in some way, helped them identify and feel assured by the goodness they exhibited through their decision making and of the rich personal qualities they possess.

The study is also significant to me personally. Beginning in my youth, topics of equity have risen to the surface of my academic pursuits but it was the many exposures to sibling experiences at the House that pushed me to zero in on this student body specifically. Through narrative inquiry, the participants and I ventured to places never explored by them outside of the family and in doing so, I hope to shed significant light on their learning journey.

Additionally, by highlighting the complex web of circumstances threatening the health of one's relationship with education and school, this study expands on existing discourse in education policy pertaining to students located between education systems and localities. Specifically, it invites critical thought and consideration of including children in democratic decision making, children's rights as temporary residents, how we define learning spaces and the child's right to an equitable education.

Chapter Summary

The study was designed around the following research puzzle: how school-age siblings of seriously ill children understand and perceive their school and education experiences when a child in the family becomes seriously ill and draws the family to travel away from home for medical care. Utilizing a children's rights lens to address the research puzzle, I provide a forum for participant narratives and identities. The process revealed researcher biases and served to shift the focus of the issues away from assumptions, toward the realities of the participant children. The research process also worked to benefit the children and researcher through our respective story sharing and meaning making of a time at the House.

Arguably, the temporary residence and learning site, the House, as presented here, can be seen as a microsite identifying common issues experienced by every member of a family when affected by childhood illness. Together, the children and I commenced in the process of revealing important insights with the intention of contributing meaningfully to education discourse and policy. In the following chapter, I begin the conversation by outlining popular and timely academic examinations related to the current study's research topic.

CHAPTER 2: A REVIEW OF THE LITERATURE

In the previous chapter, I introduce the House, the school-age sibling of the seriously ill child required to travel for treatment and the need for an in-depth inquiry into the sibling's school and education journey. The literature reviewed in this section presents scholarly work on a range of ways and means the sibling of seriously ill children are impacted and concludes by stressing the need for more research on the experiences of the sibling student directly from the student's own perspective so as to accurately capture and understand the complexity of their situation, the implications to their schooling journey and to consider how their specialized and specific knowledges of their experiences can affect education policy and pedagogy.

Literature reviewed assists in answering the primary research puzzle as previously stated. To provide a foundation and thorough context for inquiry into the puzzle, the current chapter reviewed literature relating to the topics that bear most directly on this issue: the conditions and situational stressors that disrupt the normative patterns of the lives of healthy siblings, the positive and negative effects of life modifications to the sibling child, how the educational journey is impacted, and finally, I present various scholarly positions on the need for first person accounts of the experiences from siblings themselves.

Conditions and Stressors Disrupting Normative Patterns

The many repercussions of a family having to leave their home community in search of life saving medical treatment for a sick child is at the foreground of this research puzzle. The impact of childhood illness is a shared family experience, however, the lived experience of siblings is not well known. In the following paragraphs, I discuss the scope of felt effects of childhood illness on the family unit, the sibling as the third concern and the re-classification of family roles during this time.

A Change for One is a Change for All

Studies support the fact that every family member experiences some amount of interruption when the family unit is required to leave the home community in search of medical treatment for an ill child. Leaving the family home for another city or province for an uncertain amount of time can mean establishing new family routines, relying on temporary resources such as caregivers for sibling children, housing or assistance programs, redefining familial roles and restructuring relationships. Wallinga and Reed (1990) utilize the *Family Systems Theory* to provide insight of effectual changing family roles. Linda (2006) explains *Family Systems Theory*, when examined in the context of early childhood, is primarily concerned with the idea that all members of a family are interconnected and each influence the other in predictable ways. Linda (2006) states the theory zeros in on family behavior emphasizing "communication and interaction, separateness and connectedness, loyalty and independence, and adaptation to stress in the context of the whole" (p. 12). Wallinga and Reed (1990) use *Family Systems Theory* to describe how

> the members of a family are elements of an interacting system, with the underlying assumption that a change in one family member requires a change or readjustment by the rest of the family members in the system (p. 91).

The theory lends itself to support the fact that when a child is hospitalized, all family members experience effects, positive and/or negative, of the hospitalization (Wallinga & Reed, 1990). The theory can also explain why certain members react or behave a particular way when pushed to respond to a situation or point of friction (Linda, 2006).

As imaginable, many of the family stresses and changes accompanying chronic childhood illness have a severe impact on siblings and require their adaptation. Craft (1986) suggests that life modifications for the healthy sibling can include separation from siblings and parents, living in a temporary home, and the constant threat of illness. For the sibling of a sick child, these life alterations can cause great uncertainty and anxiety. But the sibling's distress comes against the larger backdrop of changes in the whole family routine, internal limitations and roles; "in the parent-child relationships and in the sibling relationship patterns with the sick child" (Hamama, Ronen & Rahav, 2008, p. 121). Fleitas (2000) states that oftentimes, roles are reappointed with little or no negotiation. The family's life modifications could see hectic days to hectic years "of running to the hospital, frantic phone calls, and tears" (Bluebond-Langner, 1991, p. 137). For the family with a sick child who travels for specialized medical care or treatment, the family must adopt the reality that unless their child is cured, a treatment plan is established or, unfortunately, the child loses their battle with the illness, they will forever be mobile and making life modifications to accommodate necessary routines, relationships, and definitions of roles to achieve the wellness of the ill child. The Family Systems Theory, as presented, has effectually assisted in childhood counselling and therapy practices, can bare important insights into how children respond to the changes in their family and how their burden may be eased.

Siblings: The 3rd Concern

During this time of adjustment and crisis, parents and the sick child often find support from medical staff, social workers, family and friends but siblings are not considered to be affected to the same extent by the family's new circumstances. Further, when a family unit experiences dramatic change to their roles and functions, research suggests that the sibling's emotional needs are met at a level less adequate than other family members (Chesler, Allswede & Barbarin, 1991; Wallinga & Reed, 1990; Craft, 1986). "When children are hospitalized…siblings at home may be ignored. There is little time and energy for the needs of the sibling" (Craft, 1986, p. 6). The experiences of the siblings seem to go unrecognized by parents (Craft, 1986).

In my experience working with this population, most families recognize the need to provide additional support and care for the well child(ren) in the family. To supplement the energy parents can provide, relatives and family friends are often asked to lend support. Ravindran and Rempel (2011), in their study of the process of grandparent involvement with siblings of preschool children with hypolplastic left heart syndrome, state that according to the grandparents who participated in their research, parents who were engrossed in the care of their ill child, did not always have the time, energy or opportunity to meet the needs of their other children. Ravindran and Rempel (2011) state concern for the sibling(s) of the sick grandchild as a "third concern" after both their adult children and their ill grandchildren (p. 170). And in the family's reconfigured and changing world, research suggests that healthy siblings often feel caught outside of the family's new reality as "life is constantly interrupted by medical emergencies that trump regular kid concerns" (Green, 2010, http://www.npr.org/2010/11/28/131644645/siblings-of-sick-kids-learn-a-life-lesson-early). Research also tells us that to avoid isolating the well child, some level of integration into the conversation or care of the ill child is necessary.

The Informed Participant

Researchers hold that a significant indicator of the sibling's adjustment and their general wellbeing during the time away from the home community is directly related to their level of involvement in the life of their ill sibling (Craft, 1986; Ray, 2007; Chesler et al., 1991). In determining an optimal amount of involvement, these researchers ask the question of where the boundary lies between informing and including the sibling in matters concerning the wellbeing of the sick child versus over-utilizing or over-informing the well sibling to the point of causing harm.

In redefining family roles and responsibilities upon leaving the home community, scholars commonly state that siblings may become caregivers, liaisons between the sick child and school and/or provide support to parents (Craft, 1986; Hannon, 2012, Barr, Daniel & McLeod, 2008; Vanderwerp, 2011; Hamama et al., 1991). As stated previously, when parents are engrossed in the care of their ill child, the healthy sibling can often feel excluded from the family and experience great loneliness due to the lack of time, opportunity and energy that parents have to give to the siblings under the new familial conditions (Ravindran & Rempel, 2011). Relevant research tells us that in the child's isolated states, siblings report worrying about what they don't know and don't see in the hospital. They shared feelings of being excluded from information on the state of their sibling's health (Fleitas, 2000; Kresak, Gallagher & Rhodes, 2009; onconurse.com, 2014; Chesler et al., 1991). In fact, Craft, Wyatt and Sandell (1985) report that in their study, *Behavior and Feeling Changes in Siblings of Hospitalized Children,* siblings interviewed who felt they had limited information on the illness of a brother or sister shared experiencing more negative changes in behaviour and feelings overall than those who felt they were provided sufficient information on the status of their ill sibling.

In an effort to combat the isolation and exclusion that siblings may undergo, research points to the benefits of making the siblings of sick children, to varying degrees, active participants in the care of the ill child, in the delivery of education to the sick child and in the care of the household during a time of transition. It is believed that intimate knowledge of and involvement in the ill child's care may alleviate the sibling's worries about the illness and one's own feelings of being left out of family business which may increase a child's feelings of control (Chesler et al., 1991).

> Siblings should be active participants in the care of the ill child…be informed family members who are not only contributing toward family coping, but are able to continue their own growth and development (Craft, 1986, p. 13).

Kresak et al. (2009) state that siblings are socializing agents for one another. The scholars suggest that by having siblings actually teach particular skills to the child with disabilities or serious illness, the child may help relieve some of the responsibility placed on the parents. The formal teaching interactions between siblings have been found to empower the child while allowing the sibling relationship to grow (Kresak et al., 2009). This responsibility of delivering educative lessons sits on top of the already heavy load on the sibling's shoulders.

Parentified Child

Research suggests that regardless of the sibling's age, in this time of transition, siblings will adopt some amount of parentified role by acquiring responsibilities normally taken by adults in an effort to care for themselves and/or relieve parents of adult responsibilities (Craft, 1986; Hannon, 2012; Barr et al., 2008; Vanderwerp, 2011; Hamama et al., 2008; Fleitas, 2000). While siblings can feel pride in helping their parents, there are dangers in accepting or expecting the healthy child to assume roles normally filled by adults (Healthychildren.org, 2013; Hamama et al., 2008). Hamama et al. (2008) maintain that when a child adopts a parentified role within the family, this affects the child's self-concept and self-assessment, and may lead one to experience role overload. Role overload refers to an "imbalance between the role demands placed on the individual and the resources at the person's disposal to meet those demands" (Hamama et al., 2008, p. 122). Hamama et al. (2008) explain that overloaded individuals find themselves required to do more than they are able to in the time available to them or require specific knowledge or skills that lie beyond their capabilities. Not only may the parentification of a child be a significant source of stress, Chesler, Allswede and Barbarin (1991) explain that parentification may prevent the unique and separate development of the sibling's own identity. Scholars suggest that although siblings may automatically assume a parentified role, relying on the child to perform tasks beyond their capabilities and maturity level during this time of great stress can cause severe and possibly long term damage to the child. Greater role overload was linked with higher levels of state anxiety and psychosomatic symptoms (Hamama et al., 2008). Finally, researchers warn that when the sibling child assumes various adult tasks in the absence of, or to support parents, what parents, medical and teaching professionals may actually be viewing is the child's conformity to expectations (Healthychildren.org, 2013; Vanderwerp, 2011; Chesler et al., 1991; Hamama et al., 2008**)**. Siblings may actually resent the increase in tasks, and feel forced to step up in the absence of a parent in the home (Fleitas, 2000). Scholars state this is particularly true if younger healthy siblings are present in the home to care for (Healthychildren.org, 2013; Vanderwerp, 2011; Chesler et al., 1991; Hamama et al., 2008). Further in the current study we see parentification come to life in the day-to-day activities of the participants in this study.

Challenges and Opportunities from Family Life Modifications

When a healthy child must accompany the family unit to another city or province for the purposes of seeking specialized medical treatment for a seriously ill sibling, there forms a broad spectrum of potential consequences and outcomes to the well child. As expressed, leaving the home community requires being removed from one's school and friends, the family's place of residence, the community and other significant points of familiarity for an undetermined amount of time. The majority of scholars maintain that during this time of modification, siblings experience feelings of significant stress, isolation, deprivation and loss of control. In contrast, researcher studies support the notion that through distress siblings are able to acquire specific competencies from their experiences such as increased appreciation, resilience and empathy (Bluebond-Langner 1991; Onconurse.com, 2014; Fleitas, 2000; Chesler et al., 1991; Hannon, 2012; Leonard, 1991; Wallinga & Reed, 1990). The merits of the two positions are examined here.

Costs to the Sibling

As a result of the family unit's modifications during the search for life saving medical care, researchers report the well sibling as having to undergo a variety of adverse effects: feelings of loneliness, of isolation and exclusion from the family unit, a loss of control, an increase in the amount of responsibility they are asked to perform in the home to support the family unit, and feelings of fear for the uncertainty of the well-being of one's ill sister or brother. Additionally, scholars report, when interviewed or surveyed, the sibling child frequently expresses a desire to have their normal life back and often display resentment or blaming of the sick child for requiring the family to move away (Onconurse.com, 2014; Hannon, 2012). Healthychildren.org (2013), an online parenting website published by the American Academy of Paediatrics, in the article titled *Siblings of Children with Chronic Illness,* suggests siblings specifically hold the sick child responsible for the increase in tasks the well child must perform for the family unit. This is understandable given the complexity of the situation children find themselves in without preparation. The perceptions of the children were examined extensively by Bellin, Kovacs and Sawin (2008). The authors conducted a study of 155 siblings. The participants responded to an open ended question included in an anonymous self-administered mail questionnaire designed to enhance awareness of how adolescent siblings experience spina bifida (Bellin et al., 2008). The study findings were sorted into four overarching domains which depict:

> emotional complexity, intense and confusing emotions that may spring from the challenges and opportunities associated with spina bifida: rewards and consequences, journey toward acceptance of spina bifida, emotional climate of siblings, and qualities of the social environment of siblings" (Bellin et al., 2008, p. 199).

Within these domains, the authors identified important themes which surfaced from participant feedback. Struggles with guilt, deprivation and feelings of embarrassment were repeated throughout the study (Bellin et al., 2008). Guilt was recurrent in many ways including feelings of survivor guilt. Healthy sibling children shared asking why their brother or sister became ill and not another child or even themselves (Bellin et al., 2008). Guilt and shame were reported in the narrative of this sibling, questioning how one could complain "when I should be stronger because my sister has been through so much" (Bellin et al., 2008, p. 204). The child expressed feeling deprived of valuable parental time and attention now given to the sick child, and of feeling socially restricted after being removed from one's school, and social network (Bellin et al., 2008). Additionally, the limitations commonly placed on family activities out of fear of infection to the sick child were cited as common points of resentment (Bellin et al., 2008; Craft, 1986). Some respondents said they felt as though, due to the imposed limitations on the family, they missed opportunities to be typically maturing, socializing and experiencing youths (Bellin et al., 2008). Finally, embarrassment was a pervasive response from study participants. Bellin et al. (2008) share findings which suggest participants recognize struggling with public responses to the appearance of their ill family member. One participant commented that the embarrassment of her sibling's physical differences made her want to "curl up in a hole and disappear" (Bellin et al., 2008, p. 204). This factor of potential embarrassment may also play into the early finding of children avoiding conversations with others about their sibling's ailment.

The findings from healthy siblings of seriously ill children speak to the critical need to help siblings understand clearly and appropriately, to the child's capacity, the circumstances that lead their sibling to fall ill, to understand that they are not to blame for the family's new found circumstances and that they are also not expected to keep their feelings, thoughts and fears to themselves. It also asks one to consider the role of the sibling; can the child be too informed? Or is there substantial value to including the sibling in the care of the home and sick child?

Benefits to the Sibling

There is a growing body of literature centred on the costs and benefits of being a sibling of a seriously ill child requiring specialized medical treatment. Fleitas (2000) classifies the responses to sibling illness as either reactions of stress or reactions of resilience. Almost every piece of literature reviewed for the purpose of this paper that analyzed the effects of childhood illness on the healthy sibling of a seriously ill child acknowledged that there was at least potential for the well child to grow and exhibit characteristics of resiliency (Hannon, 2012; Fleitas, 2000; Vanderwerp, 2011; Wilkins & Woodgate, 2005; Healthychildren.org, 2013; Green, 2010; Chesler et al., 1991; Leonard, 1991). Accordingly, each of the five participants in my study expressed growth opportunities and/or experiencing some benefit to leaving the home community to accompany the family. Scholars describe a broad range of potential positive outcomes to the development and wellbeing of the sibling including a realization of greater resilience, empathy, increased appreciation for one's own circumstances, and the development of specialized knowledge. Growing family closeness was also reported by the majority of scholars who looked at the effects of chronic childhood illness on a family.

The development of advanced levels of resilience in siblings is of growing interest to scholars studying how siblings are affected (Hannon, 2012; Fleitas, 2000; Vanderwerp, 2011; Chesler et al., 1991; Bellin et al., 2008; Bellin & Kovacs, 2006). Bellin and Kovacs (2006) draw on literature addressing resilience in youths experiencing adversity to inform social workers of how to better promote positive outcomes among well siblings. The authors state that despite widespread agreement about viewing the impact of the child's health condition as a shared experience on the family, data is limited on the adjustment of siblings and, perhaps most significant, how to nurture resilience in this special population (Bellin & Kovacs, 2006). The topic of sibling resilience and fostering this quality in the child has drawn many positions on how to define resilience. The Oxford Dictionary (2014) defines resilience as "the capacity to recover quickly from difficulties; toughness" (http://www.oxforddictionaries.com/definition/english/resilience). Bellin and Kovacs (2006) recognize that some researchers describe resilience as a set of "positive behavioral patterns and internalized capacities demonstrated under adverse circumstances" (p. 210). However, it is Bellin and Kovacs' (2006) position that there is no singular attribute or characteristic that is protective across all life experiences, thus lending support to conceptualizing resilience as an evolving process. Chesler et al. (1991) support this notion of resilience as a method saying "many of these sibling's reactions, although disruptive upon emergence, may in fact represent an adaptation process to a unique life stress" (p 22).

Bellin and Kovacs (2006) maintain resilience emerges from an ongoing interplay between risk and protective factors but state that the nature of the interaction remains debatable among scholars of resilience. Risk factors are defined as the “individual attributes, familial characteristics and environmental conditions…that increase the probability of onset, digression to a more serious state, or the maintenance of a problem condition” (Bellin & Kovacs, 2006, p. 210). Examples of such individual, familial and environmental conditions may include the redefinition of familiar roles and relationships, increased expectations of the sibling child and the removal from one’s home school and community. Protective factors are those “assets that eliminate or decrease the negative consequences of being at risk” and are observed in the respective individuals, families and environments (Bellin & Kovacs, 2006, p. 210). These factors can include providing siblings with opportunities to speak openly about their feelings and experiences, investigating ways for the child to receive an equitable education in the temporary city, and by ensuring the child is not overburdened caring for the household or other well children in the absence of the parents. Bellin and Kovacs (2006) recommend providing the child with age appropriate, accurate information about their sibling’s health condition. They add that the natural responses to their experiences, both positive and negative, are essential in producing sibling resilience (Bellin & Kovacs, 2006). Bellin and Kovacs (2006) and Fleitas (2000) respectively hold sibling resilience to stress as an indication of personal growth, maturation, sensitivity and empathy.

Empathy and the increased appreciation of one’s own abilities as growth opportunities resurface throughout the literature. The advanced levels of empathy which siblings are capable of achieving is recognized by many scholars (Bellin et al., 2008; Hannon, 2012; Vanderwerp, 2011; Wilkins & Woodgate, 2005; Healthychildren.org, 2013; Green, 2010; Chesler et al., 1991). Bellin et al. (2008) hold the experience of having a sibling with a chronic health condition as a means of increasing the healthy child’s empathy for people with chronic conditions other than their sick sibling. This is believed to provide evidence of a larger capacity for patience and sensitivity (Bellin et al., 2008). In their study of the siblings of children with cancer, Chesler et al. (1991) argue that siblings show more compassion and empathy than is typical for the ages of their study participants; “I had to comfort people and experienced some things that most people my age don't” shared one participant (p. 33). Scholarly research focused on resilience also tends to look at how living with different chronic illnesses may facilitate the development of prosocial behavior in the siblings of sick children. Bellin et al. (2008) suggest siblings, due to their awareness of the potential mortality of one's sister or brother and exposure to other seriously sick children, develop deep feelings of privilege to be able to meet many people and feelings of respect for seriously ill individuals (pp. 204-205). Data in the current study supports this notion by way of non-formal conversation with the parents of participants. Parents of the majority of the children shared their thoughts about the positive aspects of having a chronically ill child in the home on siblings. Tom's father suggested not only had Tom received the opportunity to learn about his sister's illness and limitations, in the process Tom learned a deep appreciation of his own gifts as a skilled communicator (Personal Conversation with Tom's father).

Bellin et al., 2008, Koch-Hattem, 1986, Kresak et al., 2008, and Chesler et al., 1991, all recognize the development of the sibling's specialized knowledge due to their chronic exposure to and awareness of medical conditions. Chesler et al. (1991) suggest that some siblings noted having gained increased amounts of information and expertise related to their sister or brother's medical condition like participant Tom who maintains the functionality of his exposures as essential to articulation of his sister's conditions when speaking to children at school. Bellin et al. (2008) acknowledge that the development of unique knowledge and the diversity of responsibilities such as an involvement in caregiving for their ill brother or sister can differentiate these youths from their peers, providing an opportunity for the sibling to feel unique and accomplished. Bellin and Kovacs (2006) state that families of youths with a chronic condition may encounter major stressors and challenges, state that researchers and the family as a whole could potentially emerge stronger and more resourceful from the experience of having a seriously ill child in the family. Further, by stressing the positive contributions of the child with a disability, parents may help siblings develop a balanced and positive outlook on the family's circumstance, strengthening the relationship between sibling children (Kresak et al., 2008).

Impacting the Educational Journey

Of the limited amount of investigative research exploring the ways families are affected, several scholars have delved into the educational realm of the sibling. Of those, it is noted that siblings of chronically ill children are at risk for developing school related problems (Bellin et al., 2008; Bellin & Kovacs, 2006; Chesler et al., 1991; Hannon, 2012; Nisselle, Green & Scrimshaw, 2010; Hewitt-Taylor, 2009; Wallinga & Reed, 1990; Wolfe, 1985; Sullivan, Fulmer & Zigmond, 2001). Hannon (2012) suggests it is essential to recognize that the negative outcomes associated with the sibling's lived experiences such as an increase of stress, being withdrawn from one's school and growing responsibilities can have significant implications for one's education. In the following paragraphs, I locate the recent scholarly work in the context of the sibling's learning journey, describing how serious illness of a child may influence the education and school experiences of the well siblings. Scholars emphasize the impact of increased stress and mobility on school attendance, and issues of access and equity. I discuss relevant findings on adequate academic support for the sibling student, complications to their education attainment, and the role of education policy in supporting the student. Last, I present the importance of engaging youth in the conversation and including the perspectives in research to fully understand their education experiences and recognize the individual's full citizenship.

Stress and Mobility on School Attendance

Most seriously ill patients must travel a distance to receive specialized hospital treatment. Accompanying a sick child is typically at least one parent or guardian and often the school-age sibling(s) of a sick child. Such is the case for all of the participants in the current research. This means that for both the sick and well children in a family, life transplantation can cause extended school absences, creating significant stress and barriers to continued education (Nisselle et al., 2010). To this point, Craft, Wyatt and Sandell (1985) interviewed one hundred twenty three siblings to study behavior and feeling changes in siblings of hospitalized children and found a substantial relationship between reported change in the sibling child and residence change. The scholars reveal evidence of eighty-nine siblings in their study who stayed in their family home during the hospitalization of a sick sibling reporting significantly fewer changes than those who were taken out of the home (Craft, Wyatt

& Sandell, 1985). As an added element to the stress a child may experience due to frequent mobility, Nisselle et al. (2010) found extended school absence to place children at risk of compromised social wellbeing, academic failure or disengagement from school. In addition to being removed from one's home school to accompany the family unit, well school-age children frequently experience school absences due to familial fears of receiving an infection or virus from classmates and transmitting it to the ill sibling with fragile health (Sullivan et al., 2001). While evidence suggests reason to be alert to the risks associated with institutional disengagement, who should shoulder the responsibility of safeguarding the child's relationship with learning?

Hannon (2012), in his investigation of how to respond to the needs of the siblings of children with disabilities, notes the necessity of school counselors to help siblings manage stress. According to Hannon (2012), school counselors play an essential role based on their ideal positioning within the school to help support these students. The role of the counselor is thought to be essential given how stress may impact academic performance and success (Hannon, 2012). Building on the discussion of academic disruption, stress on the student's academic performance and mental state is investigated in studies by Chesler et al. (1991) and Craft et al. (1985). The scholars state that the child participants in their respective studies shared feeling great concern for an ill sibling making it very difficult for them to concentrate on schoolwork (Chesler et al., 1991; Craft et al., 1985). This point ties back to the need to inform the well child(ren) of medical developments to an extent. It provides some amount of empowerment to the child and allows one to function in and out of school at a level similar to that which they enjoyed before displacement. Without this information, as seen with Tom in the current study, students may elect to withdraw from their learning institution altogether for fear of being left out of an information loop.

Sullivan et al. (2001) examine the role of school for children coping with childhood Acute Lymphoblastic Leukemia. Among their many findings, Sullivan et al. (2001) note absence rates of sick children to range from twenty-seven to 170 days per year. There are no comparable statistics in the research for the siblings of sick children who leave their school to accompany their ill sister or brother following diagnosis and during treatment. However, I suggest school-age siblings experience a similar rate of absence as the ill child when the ill child is required to travel for specialized medical care. Wolfe (1985) warns generally decreased attendance equals decreased achievement for all. Arguably then, mobility and consequent absences from school may serve to create additional anxiety and stress for the sibling student.

Issues of Access and Support

Wallinga and Reed (1990) state parents in their study report well siblings developing a variety of school problems upon the hospitalization of a child in the family. Similar to the *Family Systems Theory* utilized by Wallinga and Reed (1990), Hannon (2012) holds that when considering a sibling of a sick child in the school context, it is essential to be “cognizant of how a child’s ecology and family influence their day-to-day experiences and the reciprocal nature of that influence” (p. 4). These influences, researchers suggest, can position sibling students as a form of academically disadvantaged and at risk youth (Wolfe, 1985; Bellin & Kovacs, 2006). Additionally, some of the difficulties siblings experience are identified as being due to the lack of continuity between services available in different school localities, specifically the school of origin and the temporary schools attended. This can be, in part, because of the fact that their unpredictable attendance makes it difficult for parents and teachers to manage their education and no policies are in place to support this group of uniquely challenged learners. Bellin et al. (2008) state that accessing resources and support both formally and informally such as those allowing for school adjustment and re-entry can be difficult for siblings to acquire. Wallinga and Reed (1990) suggest various ways in which schools can support these special students: ensuring regular contact between the home school and temporary host school, encouraging peer communication and providing re-entry support for the student. Contributing to scholarly research on sibling entry, re-entry and academic success, Nisselle et al. (2010) state,

> children absent from school… are more inclined to reintegrate into school more successfully when there is flexibility in their learning timetables and curriculum, responsible, inclusive and personal approaches to their learning,

> availability of appropriate support services and education staff with the awareness and skills to support children (p. 104).

Considered together, it is evident that this group of students require special provision when considering how to provide an equitable education. With the significant risk of academic disruption, it is essential to source those who can provide the added care and support this group of students require.

Importance of Sibling Perception and Policy Implications

Research pertaining to educational impacts of siblings of seriously sick children is extremely limited. While scholars have begun to look at the general experiences of parents and siblings of ill children during diagnosis and treatment of a condition, investigating and collecting data from siblings first hand through interviews and/or surveys is exceptionally rare. The majority of the research literature in this review speaking to the healthy child's education experiences are derived from adults in the child's environment; parents, teachers, school counselors or medical professionals. Of the authors that call for added attention to the unique experiences of the school-age well sibling (Chesler et al., 1991; Hewitt-Taylor, 2009; Kresek et al., 2009; Leonard, 1991; Wolfe, 1985; Wilkins & Woodgate, 2005; Koch-Hattem, 1986; Woodgate, 2000), all acknowledge this group of students as largely absent from academic research literature. Chesler et al. (1991) suggest at most research renders the children "as objects rather than as subjects of inquiry and as of peripheral rather than central interest" (p. 22). To this point, the authors call for more and better research on the experiences of siblings of children with illness. They go on to state, "only if we attend to the actual experiences of young people can we understand how to serve them better and help them grow" (Chesler et al., 1991, p. 38). Although literature on the sibling experience has increased in the last few decades, scholars suggest our understanding has not and that perspectives of siblings should be analyzed much further to contribute to future educative policies and pedagogical practices (Kresak et al., 2009). Experiences of children are discussed as important indicators of what is needed to facilitate high quality education. Sibling students facing great mobility to accompany a sick brother or sister to a new city are thought to hold specific knowledge by Hewitt-Taylor (2009). Further, speaking to the value of this student population's perceptions, Wolfe (1985) submits we must derive policy suggestions from the experiences of those uniquely challenged. Theorists stress the fact that, in times of great emphasis on a sick child, because parents are not acutely aware of all sibling changes, they are therefore not qualified to provide an accurate depiction of what their well child(ren) experience. This is evidenced by Craft (1986) who suggests that research often shows parental and sibling perceptions differ greatly on sibling feelings and behavior. The point cannot be missed that children carry an abundance of valuable knowledge that, when listened to and considered seriously, can only improve upon current practices and policies.

Chapter Summary

The literature reviewed provided an abundance of information of the complex and evolving state of the family. With the intrusion of a medical condition, each member of the family is called to make adjustments for the greater good. Knowing of the challenges illness can place on the unit, it is easy for outsiders to assume, as I did, that the well children of the family are primarily hindered. While the literature suggests the children may in fact suffer feelings of stress, fear, isolation and guilt as their life is overshadowed, they may also find opportunities for greater identity development and strong sense of agency throughout the struggle. The review of literature affirms that there are indeed chances for children to grow and benefit through the illness of a sister or brother. Among the benefits highlighted are qualities of resilience, increased empathy, appreciation for one's own healthy and a growing knowledge base specific to the sibling of a seriously ill child.

Through the costs and benefits to the life of the well child(ren) of the family, the costs are extended to one's relationship with education. Scholars assert that the well child's struggle for educational continuity while displaced is very similar to that of the ill child's level of disengagement and yet the well child is largely absent from academic research and education policy. This fact draws calls for the need for first person accounts of the experiences of the siblings and recognition of the fact that experiences broadly are educational. Knowledge development and sense making occurs both in and out of the classroom and only through direct involvement in the research can these facts be realized.

In the following chapter, I describe the steps taken to move closer to realizing the children in the academic field. The research method, narrative inquiry, is introduced followed by the tenets of my research design – both are integral to addressing the research puzzle alongside the participants in the current study.

CHAPTER 3: METHODOLOGY

As I conceptualized the research puzzle and performed a review of the literature, I found that although many education studies involve children as their population, rarely are children themselves consulted or included in the research process which represents them. It is my belief that the inclusion and contribution of children as co-constructors of knowledge in research is critical to the design of an inclusive, and supportive education system which recognizes the child's full citizenship. This is essential to achieve uninterrupted learning between permanent and temporary residences and to prepare students for long-term academic success. For these reasons, I chose to utilize the qualitative methodological approach of narrative inquiry in the current study.

The methodological design provided a means of presenting the perspectives and experiences of this group of students while including the researcher's past to locate one's self in the research. As explained in paragraphs to come, I did not realize when I committed to narrative inquiry that this would require me to visit, revisit, tell and retell my own lived experiences; some uncomfortable or unrealized memories and stories of my past and present. As disruptive as I found the personal inquiry process initially, this exploration ultimately deepened my connection with the participants, parents of participants and shone a light into new corners of the research.

This chapter introduces the methodology that frames how I present my data and my interpretations. I begin by describing the case for narrative inquiry in this research. My personal narrative and connection to this study is discussed which serves to position me along the plotline. Following, research design and process, description of participants, conversations and many aspects of the data collection process are shown. Finally, I debate the analysis techniques employed. My objective is to make visible the voices, feelings and beliefs shared by the child regarding their education and school journey when required to accompany the family in search of medical treatment or care for a seriously ill sibling.

The Case for Narrative Inquiry

According to Connelly and Clandinin (1988), "narrative is the study of how humans make meaning of experience by endlessly telling and retelling stories about themselves that both refigure the past and create purpose in the future" (p. 24). Through recollection of experiences over a period of time, stories of our past are constructed and these constructions help assign meaning to our lived experiences (Connelly & Clandinin, 1990). This methodology realizes the perceptions of participants as individuals to be understood and not measured (Sarantakos, 2005). To assist in inquiring into stories narratively, Clandinin and Connelly (2000) created a set of symbolically termed three-dimensional narrative inquiry terms; temporality, sociality, and place. The scholars state that

> using this set of terms, any particular inquiry is defined by this three-dimensional space: studies have temporal dimensions and address temporal matters; they focus on the personal and the social (sociality) in a balance appropriate to the inquiry; and they occur in specific places or sequences of places (p. 50).

Clandinin and Connelly (2000) relate the sociality and temporal dimensions to directions—"inward and outward, backward, and forward" (p. 50). They define the directions as follows:

> By inward we mean toward the internal conditions, such as feelings, hopes, aesthetic reactions, and moral dispositions. By outward, we mean toward the existential conditions, that is, the environment. By backward and forward, we refer to temporality—past, present, and future (Clandinin & Connelly, 2000, p. 50).

The dimensions assist in telling stories of a past that frame present narratives. Utilizing the three-dimensional inquiry space, narrative inquiry is appropriate in this study because it supports the aim of researching and exploring the perspectives of children as their internal conditions change over time, their immediate environments change, as well as their physical landscapes.

Children are Knowledgeable

It is my position that siblings of sick children have distinct schooling and education experiences when they are required to leave their home, community, school, and social settings to travel with the family unit. The beliefs and understandings of this group of students provide them with important viewpoints of implications felt due to education policies and practice. I also hold that children have the ability to make sense of their lives and give meaning to their perspectives. Their thoughts and feelings are valid without the input or consideration of an adult viewpoint. For this reason, I chose not to formally invite parents to be interviewed but rather converse with the sibling students alone. That said parents were able to provide unofficial comments to the researcher due to the need to gain permissions and communicate with the minor age children. The choice to base the research on the children alone was to acknowledge that to not include the explicit stories, thoughts, and memories of the sibling students, they inevitably become a topic of conversation instead of part of the conversation. They remain invisible to the education system and nonexistent in academic research. I felt strongly that to make visible their many personal understandings, feelings and perspectives during the time(s) away from their home community, they must be interviewed directly.

This methodology also allows for the profound relationship between participants and researcher to be positioned at the foundation of the research, highlighting how they are bound in a knowledge creation process (Mertens, 2005). Positioning the child participant prominently in partnership with the researcher as a co-author as done here serves to empower the student, and emphasize the importance of their input and further development of one's self-agency. The participant as co-constructor of knowledge signals that the child possesses information that stands apart from adults perceptions, and that the child's alone are critical for systemic progress and development to more inclusive and supportive policies.

Additionally, the methodology assists in revealing that siblings' experiences differ from province to province, school to school and family to family. Each participant in the current study resided in a community more than 45 kilometers outside of their temporary residence at the House and each carried with them their own particular circumstances guiding their respective journey. Holding participants as knowledge creators from different parts of Canada served to remind that regardless of circumstance and residency status, it is imperative that education systems adjust to fit the learner's needs instead of requiring students shift to meet the demands of the system.

Finally, the intimate and thorough process of utilizing the narrative inquiry process allowed me to capture the feelings, reflections and projections of the participants as they presented their stories. Before I may present the findings however, I have chosen to reveal pieces of my own narrative pertaining to this study. This is supported as an essential component of the methodology. Clandinin and Connelly (2000) state "one of the starting points for narrative inquiry is the researcher's own narrative of experience, the researcher's autobiography. This task of composing our own narratives of experience is central to narrative inquiry" (p. 70).

Researcher in the Midst

The informal starting point of my research began with my own narrative. My narrative is important because the research puzzle has emerged from my experiences as a child, student, from the interactions I had with participants while working at a temporary residence, my work on the *House Education Program* and from the absence of the topic in academic literature. It is the overlapping of selves as a non-profit professional, student, education equity advocate, and friend to the families at the House that provided the foundation for my search and shaped my narrative inquiry path.

As a researcher and student of narrative inquiry, I recognized that I must begin by exploring my past, revealing biases and allowing myself to feel vulnerable in the process before I developed a relationship with the participants in a research context (Hollingsworth, 1990; Peshkin, 1988; Clandinin & Connelly, 2000). Not only was this a necessary research activity, I wanted to be prepared to share my narrative before I asked the research participants to share theirs. Hollingsworth (1990) supports the need for the researcher to be vulnerable in research and be cast in as critical a perspective as the researched; "the investigator is not an invisible, anonymous voice of authority, but appears as a real historical individual whose beliefs and behavior must be open to critical examination” (p. 4). The whole concept of vulnerability and being exposed did not thrill me but by revealing myself and sharing my narrative, I hoped to challenge the traditional hierarchical power dynamics which can exist between the researcher and participants as well as place myself in the process alongside the student participants. As suggested by Kirby and McKenna (1989), this serves to add another layer of data to the research. To this point, undergoing the research and data collection called for the creation of a new type of relationship to be layered on top of the existing relationship. The intimate and informal connection between me, the children and their families expanded to include the functional title of *participant/co-author.* Described in coming paragraphs, engaging in my personal narrative was not an easy or welcome experience but ultimately it is the exposition of my own storied past that helped me locate myself in the research and helped forge the bond with the participants. The process also served to reveal and deconstruct the preconceived opinions I held of the education and school experiences of the siblings prior to any exchanges. Once in contact, my narrative allowed me to provide support to the articulation of their stories and to the continuation of their journey.

My Narrative Beginnings

The First Class

I claimed the last spot in Dr. Jean Clandinin’s session, *Narrative Inquiry*, that winter semester of 2013. On the first day, I recall walking into a large open room with an array of mugs to the left of the door, tea kettle and large assortment of teas. There were two large leather sofas and two chairs around a coffee table straight ahead, pictures and tapestries hanging on the walls and to my right, chairs were arranged around the tables forming a circle. Displayed in the middle were what I imagined to be artifacts from Dr. Clandinin’s travels or gifts from students. It was a very intimate and kind space. The learning environment was unlike any other during my academic career. To me, the construction of the room served to confirm my suspicions of the little I knew of narrative inquiry – I was entering into a culture of shared storied experiences and feelings. Instantly I felt uncomfortable.

Dr. Clandinin welcomed her new students warmly, asking us all to introduce ourselves by providing some information: where was I from, why did I enroll in this class, what was my area of study and any other interesting facts I was comfortable departing with. I don't remember what I said that day when it was my turn to speak but I assume, knowing my hesitancy to disclose emotional details of my personal life or anything of a revealing nature, I didn't elaborate beyond the minimum of what was asked of me. I recall leaving class that evening thinking, 'how will I become comfortable enough to speak on details of my past with people I do not know?' I immediately went home and began shedding my thoughts and feelings onto paper: how did the physical environment created by Dr. Clandinin influence my experience in the first class? What role would a culture of sharing play in my process of telling, reliving, and re-telling my stories? Did the reciprocal nature of the class and, ultimately, the methodology impact my perception of engaging with my fellow students and instructor? I wondered, if I was nervous to look into my past and share these thoughts and feelings, would my participant students feel as terrified sitting down with me when asked to relive and retell their stories? All of these questions became important as I considered my process as a researcher and conceptualized the experience I wished to share with the participants.

We are All Works-in-Progress

In the early weeks of Dr. Clandinin's class, the students were asked to form small groups to participate in *Works-in-Progress*. Works-in-progress groups are groups in which ongoing work is shared and responses from several individuals are given towards helping each other work through their particular inquiry task (Clandinin & Connelly, 2000). Clandinin and Connelly (2000) explain these groups as "sustained conversations in which narrative inquirers have an opportunity to share their research texts over several weeks or months as they are composed" (p. 166). The goal is through the reading of one's work aloud and receiving feedback, being able to experiment with one's narrative form until the best means of presenting participant narratives is located (Clandinin & Connelly, 2000). Once groups were established, Dr. Clandinin asked the students to determine what task each would like to accomplish in the coming weeks during this intimate time in our works-in-progress groups. I assigned myself the task of understanding how to utilize the methodology while meeting my desire to explore my hypothesis which positioned siblings as I viewed them; underserved and marginalized group of students. I also wanted to explore my curiosity for this particular group of students and uncover additional reasons for selecting them study beyond the obvious connection through the House.

With the encouragement of my works-in-progress partners, I dove into a process of self-discovery beginning with the latter task. I began simply; writing about my typical school days and weekends growing up. As a child, it seemed as though I was enrolled in every lesson imaginable. My father picked me up every day from school from grades one to nine, often withdrawing me early from class, and shuttling me to lessons. Each evening we drove to cities up to an hour away so that I may participate in various lessons: dance, karate, kendo, singing, acting, platform diving, choir, and so on. I did my homework in my father's dimly lit minivan in between lessons every night or in the hallways waiting to be received by an instructor; 30 minutes here, 45 minutes there. In defence of this lifestyle and my father, as I reflected back through my memory bank, I recall truly enjoying the lessons I was enrolled in. I believe my father saw my joy and continually tried to multiply it for me over the years. At least, this is the story I tell myself.

Through the telling of this story, my works-in-progress partners helped me piece together a deeply rooted connection to my research topic that I hadn't identified for myself. Although due to extremely different circumstances than the siblings of sick children, I realized very similar patterns of educational disconnections in our respective youths. I identified similarities in our struggles with missing significant amounts of classroom instruction, having very restrictive social lives, feeling the stress of mounting or incomplete assignments, and not receiving sufficient academic support from one's institution and/or parents during this time. This was a moving and powerful realization for me. Because I possessed this knowledge, I was able to add another dimension to my conversations with the children and connect with the participants within this new realm. I found after uncovering this, as a student and researcher, I was much more receptive to investing in the narrative methodology. It was as if I now had enough evidence of its potential and usefulness to fully engage.

Once open and comfortable with the culture and expectations of Dr. Clandinin's session, my works-in-progress started to transition into the former task of how to marry narrative inquiry and education policy. I wanted to understand, if I believe the students felt a particular way about their education and school experiences and narrative inquiry requires that one not predestine the research findings, how was narrative inquiry appropriate and useful for my purposes? Through the sharing of my many queries and confusions, Dr. Clandinin and my works-in-progress group members helped me identify my biases that were forcing my research topic. Peshkin (1988) suggests it is the identification of one's subjectivity that permits the researcher to be "attentive to its potential to be enabling and disabling throughout the research process" (p. 17). The scholar encourages researchers to systemically identify their subjectivity as they conduct their research, comparing it to a garment that cannot be removed (Peshkin, 1988). I eventually learned that I wasn't able to see the practicality in the methodology and the potential impact of my research because I was assuming I knew how siblings felt about their own education experiences. My bias toward a negative relationship with education through the participant's journey was serving to craft a research paper without a puzzle. If pursued, this would ultimately quiet the voices of the children that I wished to make noticeable. A compliment to my organic process, Clandinin and Connelly (2000) suggest the purposes, and what one is exploring and finds puzzling, changes as the research progresses. Further, in consultation with Drs. Lynette Shultz and Clandinin, I was assisted in confirming that my goal was not to marry policy with narrative inquiry. Through inquiring into my own narrative, and with the assistance of both Drs. Shultz and Clandinin, my position changed with the research; I was not attempting to prove a hypothesis but rather provide a generous space for the siblings to appear in research in their own voices, sharing their learnings as they have defined them through the telling, retelling and reliving of their stories and mine.

Method

Participation

While working at the House, I had the honour of being included in the lives of many families. Usually over coffee in the morning or while preparing a meal in the kitchen at the same time, I received frequent updates on at least one family's stay and the health status of their ill child – good or bad. During conversation, I too would share the events of my life including that of my graduate program. My research puzzle seemed to intrigue certain families so recruitment of participants proved unforced. Over time, the families displaying interest either asked how they could contribute to my research or I approached the family unit for consent to contact them once I began my thesis.

The study participants consist of five school age children**.** For clarification purposes, an individual is referred to as a child as long as he/she was under the age of eighteen per The United Nations Convention on the Rights of the Child (1989, Article 1). All five students in the current study travelled with their family frequently between 2010 and 2012 when the seriously ill child's condition required that the entire family leave the home community for an uncertain amount of time. The participants all resided at the House and had the opportunity to attend the resident Education Program to subsidize the formal education received in their home community school. As mentioned previously, the Education Program, although staffed by a licensed educator, is not an accredited program.

Inclusion in the study was limited to those who were eighteen years old and younger, who permanently resided outside of city limits, were enrolled in an education program in their community of permanent residency, and temporarily resided at the House. Another delimitation to participation was the positionality of the participant's parent(s) or guardian(s). All caregivers shared with me that they agreed with key tenets of my research: children do have distinct perceptions of experience, learning can occur outside of formal environments and children possess thoughts on their journeys that differ from adults' perceptions. Therefore we all agreed that children should be interviewed directly and without legitimization of parental input. This served as the first filter to identifying those families permitting children to be included in the study independent of other family members.

Once participation was confirmed, I provided each family with an introductory letter, letter of consent form for the parents and an assent form for the child (see Appendix A). The assent form doubled as the script which I read to the children to reaffirm their interest in taking part, understanding of the study procedure and the desired outcomes of participating in the research. The information letter detailed the study, and outlined requirements of the child(ren) participating. In addition to explaining the nature and purpose of the research, the informed consent form made adults and participants aware that the child participant(s) may ask questions about the research at any time during the entire process, they may opt out of the study until a certain point in the process, and that they were guaranteed anonymity and confidentiality. As well, adults and participants were informed that the child(ren) may request to review transcripts, revise, clarify or eliminate portions they contributed to the research also up to a certain point in the research process.

Upon having the forms sent back to me, I called or emailed the participating families to establish a time to hold conversations at their convenience. When possible, meetings took place either in person at a participant's home at the House. When I was unable to travel to the residence of a participant or they did not anticipate a trip to Alberta, we utilized online tools Skype or FaceTime to hold conversations. This method of conducting inquiry was largely successful despite sporadic challenges to the flow of a conversation when either I or a participant had a poor internet connection.

Research Design

In conceptualizing the design of my interactions with each participant and my research goals in mind, there were many significant aspects I wished to include as we began formally and informally communicating: discussions of landscape, alternative investigative methods, developing a structured yet conversation style interaction with participants, and making space for all of the identities of the child to be present in the research. As mentioned previously, my relationship with each of the participants began very casually and flourished in the home-like setting of the House. The children came to know me as an employee of the residence but also as someone who participated in craft sessions along-side them, sat with their family at lunch and who they could have simple conversations with. For this reason, I wished to maintain the familiar connection through a carefully chosen meeting landscape consistent with the ways and means of our relationship within the temporary residence. In forming this decision, I reflected on the importance of the environment Dr. Clandinin created in her classroom to my introspective process. While I was intimidated initially, Dr. Clandinin's classroom setting came to be a place of refuge, symbol of kindness and place of comfort over time. The space and relationships formed within it allowed me to reveal memories and pieces of me. While considering the places I would invite conversation, as termed by Clandinin and Connelly (2000), I tried to remain *wakeful*, reflecting often on my experiences sharing my stories in the three-dimensional narrative inquiry space to help guide my procedural decisions moving forward.

The five participants in this study maintained permanent residency both in and outside of Alberta. In theorizing pending conversations, my hope was to travel to the home of the participants. It quickly became apparent that the cost combined with the necessary time away from my job would make traveling to perform each conversation unrealistic. For three of the five participants, it was not possible to conduct face-to-face meetings. In these instances, I spoke to the students via video conferencing tools Skype and Facetime. While this type of correspondence for the purposes of data collection is not heavily documented in research, I do not believe the use of conferencing tools compromised my data for several reasons: the children remained comfortable and secure in their homes during the conversations thereby remaining in a familiar environment near parents and/or siblings should the participant become uncomfortable at any point. At times in the process, I was grateful for the use of this correspondence format, particularly when our conversations required participants to recollect difficult times in their lives and share memories from traumatic events. It was somewhat relieving to know that should any of the children feel confused or uncomfortable at any time, they had the ability to readily seek support.

Clandinin and Connelly (2000) suggest the way a researcher acts, questions, and responds in an conversation shapes the relationship and therefore the ways participants give accounts of their experiences. With this in mind, it was important in the design of my interactions with each child to have opportunities for both informal dialogue as well as some structured questions. In doing so, the aim was to create a feeling of being in conversation. I did not strive for generalizable data here but rather to encourage free and open communication for the children to recount their experiences while identifying broad themes from the perceptions. To accomplish this I relied on the familiar relationship previously built with the children at the House and worked to establish spaces for their candid voices to be heard. Informality was also necessary given each child carries with them their own conditions and feelings. Using my knowledge of familial circumstance, age and context, I was required to re-evaluate my strategy with each student. With all of the participants, however, I built my approach with a heightened awareness and utmost respect considering possible fragility of their past, present and future. Structured questions mainly served the purposes of creating timelines through collecting historical information such as dates and sequences of events and identifying points of comparison between the learners. Clandinin and Connelly (2000) refer to this information as *annals* and *chronicles*. Time lines as told by the participants helped the researcher gather facts, provide insight into how the participants piece the events of their life together as well as help them identify their educational experiences in the landscape of theirs and their family's patterns (Clandinin & Connelly, 2000).

Yet another important consideration in the design of the research was to provide a means of highlighting the multiple identities of the children. I had chosen the participants because they fit the description of my ideal candidate but equally important was the need to present the whole identity of the child. More than the sibling of a seriously ill child in the midst of education systems, the children possess a collection of dynamic selves. To bring the other identities of participant and researcher to the study, the children and I prepared memory boxes or to show larger items that bear great significance to characterizing who we are. The memory boxes contained symbolic items such as pictures, small treasures and archives representative of our other identities while the larger items were better experienced than produced in picture. As co-constructors of the study, both researcher and participants came to conversations ready to share important and cherished items representing our other selves. This method of data collection is supported by Clandinin and Connelly (2000); “these items trigger memories of important times, people and events around which we tell and retell stories providing a rich source of memories and information” (p.114). While some of the items reflected memories generated at the House and served to keep the focus on that specific landscape, a lot of the memory box items presented evidence of young blossoming artists, decade long friendships, passionate readers, video game players and active members of a community – the equally important sides to a child requiring inclusion and consideration.

Procedure

During each conversation, whether in person or through conferencing tools, conversations were audio taped with the permission of parents and participants for future transcription. As well, field texts were constructed of my thoughts and insights throughout each meeting, mindful that audio recordings cannot capture body language and nuances. Clandinin and Connelly (2000) describe field texts as notes or dictations meant to recall observations, memories and feelings from an exchange in the field. Field texts serve as a means of helping inquirers play a dual role both in and out of the story and landscape; “always the inquirer experiencing the experience and also being a part of the experience itself” (Clandinin & Connelly, 2000, p. 81). In this sense, field texts reinforce the significant and collaborative relationship between researcher and participant. Immediately following each interview, I noted all personal reflections or observations from our meeting in my notes.

Data Collection

Conversations served as useful methods of data collection for this study. One-on-one meetings were conducted either in person or via conferencing tool using a loosely prescriptive interview guide approach. The majority of the questions were open-ended with the exception of few closed-ended questions so as to provide context to each conversation. In discussions, the same topics were addressed at a point to ensure a means of comparison between participants surfaced. However, questions were not asked in a particular order. My hope was to allow space for the child to feel a sense of empowerment through their role as a co-author of the research and therefore in guiding of conversation to an extent. This resulted in rich, colourful narratives, full of detail and authenticity.

Data Analysis

Upon completion of all conversations, I listened to the recordings of each conversation and transcribed the narrative performing formal textual analysis to identify sequences and significances of events as higher priority or lower priority. I also reflected on all field texts created during this process in concert with the many memories I carried with me of the interactions I had with the children over the years. All of these activities helped to classify the general and abstract thematic threads as presented by the participants. Parents were then emailed copies of their child's conversation(s) with me for the purpose of reviewing the transcripts and sharing them with the participant.

Threads were used when necessary to create few select follow up questions meant to collect further detail, clarify timelines or specifics of events and collect final thoughts on education and school experiences. The questionnaires provided important qualitative data through both open and close-ended questions. Interestingly, several parents utilized this email exchange as an opportunity to thank me for including their child in the current study and to provide their own insights of the education and school experiences of their child(ren). While not formally invited to contribute to the current study, their input served to add merit to several of the findings drawn from the data.

Study Virtue

Data was gathered for this study from informal discussions, formal conversations, memories of researcher/participant interactions and unofficial email correspondence with participants and parents. To ensure the quality and virtue of the study, I focused on utilizing strategies to support its validity, dependability and transferability. I employed multiple tools to accomplish these goals.

The formal activities lent themselves to speak to the validity of the research. Those included gaining written consent from the parents of participants and assent from the participants themselves. As well, during conversations with participants, I utilized an audio recording device with the consent of the parents and children. Recording our meetings allowed for our conversations to be captured word-for-word and for additional field notes to be taken. Free from writing down the words of the children, I was able to take extensive field notes, capturing the inaudible information from participants such as body language, tone inflections, and emotional displays. Following participant conversations and data transcription, the transcripts were shared with each participant and their parents to ensure accurate interpretation. Providing further support to the validity of the study was the option given to participants to provide clarity or changes to the transcript.

Dependability of the research was achieved through the use of tools: researcher journals, field notes and narrative inquiry processes such as participation in the works-in-progress group. These served to reveal, not strip, researcher biases and create more open sharing spaces between the researcher and participant. Additionally, it was thought that greater research dependability would be achieved through the pursuit of a strong relational foundation between researcher and participant. This was accomplished by coordinating conversations to transpire in locations where the participants felt most comfortable such as their personal homes or at the temporary residence. It was also beneficial to conduct conversations between myself and the entire family prior to engaging in the research to answer any questions the family unit may have. As an added support, I included the House teacher in the unofficial early conversations with those families familiar with her. The purpose of including the teacher was to assist the children in drawing a connection through their recollections of years past when they saw the teacher and I working together at the House. The teacher was also able to help the children remember facts about the classroom such as the timing of instruction, and how each child's permanent school did or did not communicate with the teacher at the House. I believe it was essential to include the teacher as she had an intimate relationship with the children, working directly with most of them periodically over the course of two years.

To support the transferability of the study, data triangulation was employed. Data triangulation in the current study involved the careful selection of children of varying ages, geographic origin and circumstance but with the common thread of traversing a difficult educational landscape as mobile students. Additionally, set against the interviews were the other forms of data collected including follow-up questions and email correspondence from the parents of participants for the purpose of information clarification. Once all data had been collected, interviews and conversations transcribed and coded, I performed a cross-case analysis to identify threads to support the transferability of the data and findings. As I pieced together the findings, transferability was achieved further through the application of as many direct quotes form the children and detailed descriptions of our interactions as possible.

Ethical Considerations

In accordance with my research plan, I provided each family with a Research Information and Consent Form (see Appendix A) which outlined the intended purpose of the study and the requirements of each participant child. The form indicated the identity of the children would be protected which lead to the removal of all identifiable information from transcripts including actual names of the participant children. As discussed previously, the form also indicated that the children could withdraw from the study up to a certain point in the research and that each parent and participant child would have the opportunity to review all interview transcriptions prior to inclusion in the study. I obtained written consent from parents of all five minors participating in the study as well as verbal assent from the children themselves through the delivery of an Assent Script prior to beginning interviews (see Appendix B).

Chapter Summary

As I worked to find my way in the methodology as an inquirer and participant in the research, I was struck by the enormous responsibility of possessing the stories of the children. Recognizing it is the subjective experiences of the participants that are at the centre of inquiry (Mertens, 2005), I wished to present their respective narratives as honestly as possible and also create a platform for further academic consideration of the educative, social and personal insights gained from their experiences. In doing both, the intent was to drive change. Building guards into the research design from conceptualization to fulfillment lent support to the potential of achieving all of my desired goals. In the coming chapter, I introduce the child participants who, like me, saw the need to bring their voices in from the dark and challenge both ontology and epistemology of education policies to consider the value of the child's learnings and perspectives formed from all of the child's identities.

CHAPTER 4: INTRODUCING THE PARTICIPANTS

In this chapter, I begin the conversation by addressing the mental state of both parents and participants in the current study. I present each participant from the facts they provided to me, from what parents shared during the research period and from the knowledge I held of the family and child(ren) from a time prior preceding the current study. This information includes facts about each child such as age, grade, and family dynamics. I also include the reasons each family traveled to their temporary city, how the participant and researcher met, subtleties of the relationship and finally, how we have collaborated and come to grow our relationship as reflected in the research.

Mental State of the Participant Family

Before I present each child, I wish to illustrate the emotional and mental states of the whole family when displaced and the many life modifications placed on them associated with medical emergencies. Figuratively presented within academic literature reviewed in Chapter 2, all of the families in the current study validate the findings as families either exhibited or shared with me many of the same feelings and/or conditions.

Often families in need of urgent care for a child must respond quickly and without a clear understanding of the duration of their stay in the foreign city. Because of this, the entire family unit is often unprepared for their new lifestyle, landscape and sacrifices required of them over the next days, weeks, months or years. Parents as well as children are faced with feeling confused, overwhelmed, fearful and isolated. As I came to know families while employed by the House and more intimately during the early informal conversations prior to the research process, each described the events leading up to coming to the temporary city for the first time as both sudden and uncertain. They also shared that while they tried to remain positive and hopeful, there were constant feelings of stress and fear through the entirety of their stay. During our interview, Tom told me that it was while his sister was being examined by a doctor for an ear issue when his father mentioned she was complaining of chest pains. After initial testing, the doctor urged the family to seek specialized medical help immediately in Alberta in order to examine her further and figure out a diagnosis. Not knowing what to expect, Tom, his parents and sister uprooted for an unspecified amount of time. Similarly, while in conversation with Brianne's mother, she shared that it was Brianne's sister's complaints of a headache that brought them to the doctor who discovered the tumor. They too immediately rushed to Alberta from another province, leaving their lives behind momentarily to face great unpredictability.

A large concern for parents is the care of the healthy child(ren) left at home. In the conversation prior to interviewing brothers Jason and Dennis, their parents told me the uncertainty of the well-being of their ill child due to the complexity of her condition caused them both to spend large amounts of time and energy at the hospital. This kept them away from Jason and Dennis most days and for the majority of the day. To provide some stability and to care for the boys, Jason and Dennis' grandmother moved in with the family from the Philippines. Similarly, Brianne's parents also relied on family and friends to care for Brianne and her brother when they were unable to do so. This dependency on others and inability to remain fully connected to all of one's children equally appeared to be a cause of tremendous guilt to the parents and source of isolation away from one's parents to the well children.

An additional area of consideration is the parent's process of coming to understand and navigate the family's role in the care of the sick child in the hospital setting. Justifiably, parents spend substantial time with their ill child. When the child is in the hospital for a period of time without an exit date, it becomes challenging for parents and practitioners to develop clear expectations of the family's involvement in the care of a child in the hospital landscape. With formal inquiry beginning largely in the healthcare sector in the 1980's, medical professionals took the side of advocating for child care practices to include family-centred care (Bruce & Ritchie, 1990). This approach positions parents and medical professionals as collaborators in guiding children's development in and outside of the hospital and emphasizes a need to understand the whole child (Widrick et al., 1991). It also positions siblings and other family members as key participants in the care provided to sick children (Widrick et al., 1991). This notion is supported by findings in the next chapter where most of parents and participants share their very strong opinions regarding their role in the treatment process and care of the ill child.

Additionally, fear and anxiety about the family's financial health is pervasive during the illness of a child. As a staff member at the House, families frequently shared their concerns of mounting expenses due to travel, food, accommodations, and daycare for the well children. These worries are made more serious when one considers that all of the parents in this study took a leave of absence from their job, used vacation time or one parent travelled between the home community and temporary community frequently to maintain a source of income while the other parent remained in the temporary city caring for all of the children. As shared with me by Ali and Jason, financial issues weighed heavily on all members of the family, and threatened significant disconnection between family members when one parent must stay in the home community to work.

Having presented common mental and emotional complexities of parents and siblings of seriously ill children, I now introduce the five participants of this study. Each child carries important information of their many selves and learning challenges and/or opportunities throughout time and in various landscapes. Their contributions require our attention. With that, I invite you to meet the co-authors of this study: Brianne, Dennis, Jason, Ali and Tom.

Co-Authors and Participants

Brianne

I first met Brianne and her family at the House in 2011. Brianne was six, her sister was nine and her brother was three. Brianne's family left their province for Alberta two separate times for testing, treatment and care of Brianne's sister between 2011 and 2012. During her residency at the House, Brianne utilized the Education Program as her only formal learning opportunity.

April 2011, a six centimeter tumor was discovered on Brianne's sister's brain. The tumor was removed and the young girl recovered quickly. Two months later, a follow-up magnetic resonance imaging (MRI) test revealed the tumor had returned. Doctors operated to remove a fist sized tumor from the right side of her brain and she underwent both radiation and chemotherapy treatments for the coming months.

During this time, the family resided at the House. I did not know the family very well during their two month stay. It was throughout their second trip staying at the House when I became friendlier and more involved with the family.

I recall seeing the family in the kitchen one morning in January 2012. I greeted the entire family, excited to see every one of them. Brianne's father told me they were planning to stay for a few days – long enough for a follow-up MRI for Brianne's sister then they would travel back to their home community early the next week. Everyone appeared to be in good spirits and very positive about the pending test. With that, I wished them well and I returned to my office. The following week a colleague informed me that Brianne's family didn't receive the news they were anticipating. In fact, the news was not good at all. The young girl had a tumor drained immediately. Following this, the family stayed for an uncharted amount of time until more tests could be performed and a treatment plan established. During this stay, Brianne utilized the education support provided by the House and when I first shared my research with the family.

Brianne's sister, for the next few months, split her residency between both the local children's hospital and temporary residence with her family. After months living at the House and Brianne's sister's health not improving, it became apparent that it was time for the family to move back to their permanent residence to continue treating her cancer in the comfort of their home. Sadly, Brianne's sister passed away shortly after.

Over the course of the next year, I communicated with the family through social media and followed the family's quest to adjust to life without Brianne's sister while honouring her memory and spirit. I watched as they worked to evolve as individuals and a family after the loss of a child. I reached out to the family explicitly to discuss Brianne's inclusion in my study. Shortly after, the House teacher and I spoke to Brianne and family via online video conferencing tool, Facetime. Including the teacher on our video call allowed Brianne and family to see several familiar faces and hopefully helping Brianne feel comfortable speaking then and in our interviews about the family circumstances that had affected her relationship with education and schooling.

The week after the group video call, I spoke to Brianne exclusively. At Brianne’s request, her mother sat off to the side of the camera. This conversation proved most challenging to me as an inquirer. I tiptoed cautiously trying to be empathetic and considerate of her feelings as I engaged Brianne in questions about her sister, their friendship and her life since her sister’s passing. This hindered my ability to gain all of the possible data I could have. The fact was recognized by Brianne’s mother. At the end of our conversation, Brianne’s mother asked if Brianne’s contribution was sufficient enough to be useful for my purposes. She urged me to ask more questions, and/or difficult questions if need be (Personal Conversation, May 21, 2013). Brianne had in fact contributed meaningfully to the research, providing significant input towards consideration of the needs of the youngest students in an education system and the areas of greatest concern to the student.

Dennis and Jason

When I met Dennis and Jason, brothers from Alberta, they had made frequent trips with their sister and parents for about three years. Jason told me he estimated his family had made approximately ten trips in two to three years in pursuit of very specialized medical care. Dennis and Jason’s sister suffers from Rohhad Syndrome:

> Rapid-onset obesity with hypothalamic dysfunction, hypoventilation, and autonomic dysregulation (ROHHAD) is a rare and complex pediatric syndrome, essentially caused by dysfunction of 3 vital systems regulating endocrine, respiratory, and autonomic nervous system functioning. (:http://pediatrics.aappublications.org/content/132/3/e788).

Over the course of their numerous trips, the brothers attempted to sustain their academic path through a variety of methods and resources: one-on-one instruction at the House, enrolling in a public school, and working independently on the lesson plans provided by their home school.

As with the other families in this study, I developed a relationship with the Jason and Dennis’ family while they resided at the House. I often spoke with the parents as we crossed paths in the kitchen in the morning before they rushed off to see the boys’ sister who was living in a local rehabilitation hospital. Inseparable, often the boys stayed at the residence together when the parents went to the hospital. Despite being supervised by their grandmother and urged to attend school by their parents, on these days, both Jason and Dennis decided whether or not to attend the House Education Program. Occasionally they opted to sleep in and join other school-age residents for academic or creative activities in the afternoon. As a spectator, they both appeared to have the autonomy to take a relaxed approach to attending class and utilizing the program as a support or supplement to their home school lessons.

In 2012, I spoke to Jason and Dennis' family specifically about my research topic. I asked if the brothers would be interested in participating. After hearing a very brief description of my research topic, both boys affirmed their interest in contributing. I contacted their father again in March, 2013. He informed me that the family recently relocated permanently to the temporary city to provide participatory care daily to their hospitalized daughter. As we planned, I suggested the initial meeting with the family and both interviews with Dennis and Jason take place at the family residence. This ensured the conversation could be relaxed and collaborative in nature. As well, if the either boys wanted familial support, their grandmother or parent(s) were close by.

At the time of the interviews, Dennis was ten years old, in grade five and Jason was thirteen years old, in grade seven. For the initial conversation with the family, I invited the House teacher to join us. The boys were students in her classroom on and off for a significant portion of three years. And with both boys being reserved and quiet by nature, including the teacher was important to ensure the brothers felt comfortable and confident speaking with familiar people about their lives. When the teacher and I arrived to the family home for the initial conversation, we were greeted by the parents, grandma and two boys at the door. Jason and Dennis' mother was on the phone with the boys' sister. Their Mom was not having a conversation with her as much as trying to be present in both places, supporting all of her children to the best of her ability.

This meeting served as an opportunity for the parents to share their recent history moving from city to city, and their frustrations regarding the demands of their new reality dictated by their daughter's conditions. The parents discussed with great regret how their new life affects the quality of life and education their sons receive. Having tried many options to locate a consistent education plan, eventually the boys enrolled into the public school system. While the brothers had structure attending a public school, the parents acknowledged that Jason's grades had declined and Dennis found it difficult to make friends and found the school environment very intimidating. Derek found it challenging to feel comfortable in a school much larger than the intimate home school he was accustomed to. Weeks after the initial meeting with the family, I came back to their home to meet with each child for an individual conversation in which their grandmother wished to observe.

Ali

I first met Ali in 2010 when she was fourteen years old and in grade nine. It was Ali's sister's health that brought the family to Alberta. In December 2010, Ali and her family made the 12 hour drive from their home for her sister to undergo a liver transplant. The fragility of Ali's sister's condition dictated the family remain close to the hospital. The family lived at the House from December 2010 to March 2011. During those months, Ali made every attempt to pursue her education and establish some semblance of a teenage social life. Ali's academic path included attending the *Special Schools Public School* inside a children's hospital, utilizing the education program at the House, and lastly, enrolling in a performing arts school to nurture her specific artistic interests.

It was two years after the family left to return to their home community when I contacted them to ask if Ali would consider participating in my study. Immediately Ali agreed to participate. Unlike other children in a similar situation, Ali exhibited a strong sense of agency in her pursuit of a formal education and social outlets. She sought support from a variety of sources and subsequently, through the reliving and retelling of her narrative, shared some very unique and exposing educational experiences for the purpose of making her voice heard.

After confirming her participation, we established a time for Ali and I to speak, just us two. A preliminary informal conversation apart from emailing back and forth was not organized to include Ali's parents and siblings. While they did briefly say 'hello' at the beginning of my conversation with Ali, they did not become involved in the interview process. It was very clear that Ali wished to participate entirely autonomously.

To conduct my conversation with Ali, we utilized online conferencing tool, Skype. This online communication tool is similar in function to Facetime, the program utilized to interview Brianne. During the time of our conversations in 2013, Ali was sixteen and finishing grade eleven.

Tom

Tom was eleven when we first met. The second youngest of six children, Tom had travelled with his family almost every time his sister suffered from her illnesses or required the attention of specific medical specialists. Tom's sister was born with a complex series of disorders including a lazy cleft palette and without eardrums causing her to experience thirty percent hearing loss. Additionally, in March 2009, Tom's sister was diagnosed with pulmonary hypertension. At the time of her diagnosis, she was just the second child ever treated in the area's children's hospital for this condition. Because her diagnosis was so rare, Tom's sister was routinely scheduled to see physicians in rheumatology, hematology, cardiology, and neurology departments. To ensure Tom could travel with the family when his sister was required to see specialists, he attended the House Education Program to supplement the home school education in grade seven and was registered to be homeschooled by his mother for grade eight.

Between 2010 and 2012, I shared the House with Tom and his family often but sporadically. A very positive and engaging family, we quickly formed a friendship. Once I told Tom's family about my pending research, they made a point of asking me about it in almost every conversation we shared. Both Tom and his father offered to participate or assist in any way possible. I wasn't surprised by their generosity. While I hope to never have to see people need the resources of the House, I was always glad to see Tom's family for a variety of reasons. One reason being my curiosity and desire to learn more about Tom after witnessing the incident in the House kitchen involving his sister experiencing a cardiac arrest. In that moment of extreme urgency, I saw Tom the boy, brother, son, and student as Tom saw himself in his most important role; caregiver and life saver.

Early 2013, I contacted Tom's father via email to discuss Tom's inclusion in my research. My interests were heavily influenced by Tom so I sincerely hoped he would consider participating in the study. Again, Tom did not hesitate to contribute. A month later, I met with Tom and his father at the House to discuss the study. Tom's father recognized how his son has been both exposed to and made part of adult appropriate situations but stated that he believed Tom was better equipped to handle life's challenges because of those exposures.

Following that conversation, we scheduled the next meeting between Tom and I using Facetime. In May 2013, we conducted our interview, determining together the duration of the conversation. I followed a loose order of topics so as to have continuity between participants and themes, but our conversation was so fluid that the pace and direction of our chat became collaboratively decided. I believe Tom enjoyed guiding the conversation, and providing generous elaboration and detail to describe his stories. Tom was fifteen at the time and finishing grade nine.

Chapter Summary

In this chapter, I describe the emotional and mental states of the participants and their parents during a difficult time from information gathered through conversation with participants and their parents. I also introduce all five participants/co-authors of the study, and their respective circumstances causing the disconnection in their educational journey. I also discuss the dynamics of the researcher – participant relationship. In the following section, I build on the conversation started here by presenting each participant's perceptions of their individual circumstances, roles, identities, education and school experiences that emerged through inquiry and analysis.

As I transitioned from field conversations to consider all field texts (data), I moved cautiously, always attempting to be mindful of the multiple identities of each child and of how each framed their own experiences in their larger familial contexts. I had identified my biases to this point, initially motivated by the belief that this group of students were underserved and overlooked by the public school system. However, as each child independently presented their personal feelings on the role of their education and their roles as sisters or brothers, I shifted my focus to issues of education equity and appropriateness. In the following chapter, I use the formal and informal conversations with my co-authors to present the youth’s narratives as shared with me centered on the research puzzle of this study. As I progress through the chapters, it is imperative to reiterate that their memories and perceptions are valuable and provide important insights into the benefits and challenges of being the sibling of a seriously ill child required to travel for medical treatment and care.

CHAPTER 5: THREADS AND FINDINGS

Reviewing field notes and conversation transcripts, a large number of specific themes emerged spanning provinces, ages and circumstances. I teased out the essential points of overlap pertinent to the research puzzle and identified areas of ease and difficulty in the youth's paths. Points of focus include information regarding each participants' views of the role of education during this time, how perceptions of the purpose of education and school had shifted from before and after being required to travel, and what resources they required for an equitable education. It was consistently apparent that each individual faced balancing a complex number of elements and tensions as they navigated their lives.

The findings for discussion are organized to begin with the lens through which all of the children applied while deriving meaning through narrative. Beginning here lends to painting a picture from which to consider the remaining themes highlighting shifting thoughts on the roles and importance of education and learning. I begin the discussion by presenting the role of the child as defined by themselves. Next, I present the described social and academic effects of displacement. Residual effects of being a displaced student are presented including the children's current position on school, education and teaching. Perspectives of the House are debated addressing the facility as residence and necessary alternative learning/socializing environment. Finally, the uses of technology are presented in terms of sustaining connections at a distance.

Providing Comfort, Care and Normality

I always had to be prepared to have a phone call to leave school but I guess it was just overwhelming realizing that I had to leave all my friends and pretty much drop everything cause that's the sacrifice I had to make for my sister (Interview, Ali)

We begin the discussion by considering how the children characterize themselves during and after trying circumstances. When I asked the children if they felt they had a task to perform during the time of a brother or sister's health crisis, each child shared their conceptual understanding of self as an agent of influence to the overall family's wellbeing. The children's ideas about their responsibilities ranged from sacrificing (as evidenced in the opening quote from Ali), feeling accountable for providing emotional support and literal care to an ill child, to supporting one's family and/or minimizing the stress that parents may experience, and providing support to other families living at the House. Each of these is debated further through the children's own words.

Supporting the Ill Child

Some version of supporting an ill sibling was plainly mentioned by the majority of the children interviewed. Common among beliefs of self-agency included being a source of emotional stability and symbol of normality. After considering the question, Ali shared that she viewed her job as that of a positive influence to her sister at all times. She stated,

> *All I could do was try to be happy around my sister all the time if she was sick in the hospital. She couldn't take any stress and I couldn't take my stress into there so it was good. I'd just go to my art class and express everything there and get my feelings out.*

Much like Ali, most of the children recognized an essentiality to remaining positive or neutral in the presence of an ill sibling. Another way the children provided support was to behave and relate to their sibling as they would have before the illness. Brianne shared that both before and while her sister was ill, their favorite thing to do together was play Barbies. This simple playful interaction between the girls served to symbolize their identities as sisters and friends before a life threatening illness had entered their lives. Mutual participation in everyday activities were revealed as intentional acts essential to relationship maintenance when threatened with distance or limited time for interaction compared to time spent together before the restraints of an illness. Taking personal responsibility for the physical wellbeing of an ill child was also deliberate.

Both Tom and Ali shared researching their sibling's respective illnesses to learn more about the infliction and to seek information on alternative medical options to a cure. For her part, Ali recognized the difficulty in waiting long periods of time for her sister to receive the medical care she required stating, "*I did try looking up things that I could do to help but, like natural ways that she could get healed, cause, you know, it's very…it's not like everyone can get a transplant.*" Tom shared how he had embraced a vital role in the resuscitation of his sister and has done so numerous times. Tom said,

> *Me personally, I didn't feel like I was doing anything but… I don't know. I don't like to say I was doing anything but I was probably being more like motivation and encouragement. Like, when (she) was doing anything, like if she had a seizure or a cardiac arrest, it was, 'run do this, get the oxygen, get the heart monitor, get it down here and be fast about it', right? I was that kind of guy. And I did play a role in a lot of things. And my parents tell me a lot of the time if I wasn't there during some of (her) really hard times, she probably would have given up.*

The roles the children claim are exceptionally varied but all are viewed as of paramount importance to them. They serve to define the child at this time and are supported through reinforcement of essentiality by parents as evidenced by Tom's quote. The following section builds on the discussion, featuring the roles and associated importance each child shared attaching to assisting their parents any way possible.

Supporting Parents

When asked if the children felt they could alleviate the negative effects felt by their parents or assist them in any other way, the common response was to take on some of the tasks within the home themselves, take care of other children in the family and try not to cause additional stress. Jason was unique among the group as the only participant old enough and expected to care for a younger sibling in the home and with a strong cultural dictation of the role of the eldest brother. I asked how he supports his parents. Jason replied that he helped by "*taking care of my brother. That's pretty much all I do*". He shared with me that in the Philippine culture, the eldest male child is called *Kuya* (Conversation with Jason). Jason said that this term is meant to suggest a position of authority and responsibility for the children younger than him. When he was nine, it was clear to him that his sister would not respect him due to her behavioral and health conditions and his little brother was simply annoying. He wanted to abandon the title and responsibility; "*I don't know... I didn't want to take care of them because my dad said that, like, it's a* *big responsibility to take care of them and I didn't want that so I wanted to give it up*". As he told me this, while his grandmother was present and they reflecting on the story in a lighthearted manner, it was clear the responsibilities of this role weighed heavily on him. It was evident that he did not feel capable of supporting his family in this traditional and culturally determined fashion. I pressed him for more information, asking how his perspective regarding his role had been actualized. He shared, *"well that changes now that (she) is in the hospital. So, it's like my responsibility to keep (Dennis) safe cause (my parents) don't have enough time for him anymore".* Despite the Kuya title and assigned responsibilities, it is Jason's ability to turn compassion inwards to support and strengthen the vulnerable family unit and his empathy for his parents that allows him to be his brother's keeper.

Jason's comment above lends itself to another method of supporting the family; the necessity to reduce stress experienced by parents by remaining relatively unnoticeable or limiting the amount of support and childcare required of parents. When probed, Dennis said that he could be most helpful to his parents by *"trying to make them not worry about me".* As previously shared, the task of his daily childcare came to rest with Jason or their Grandmother in the parents' absence. In other instances, where a guardian was not available, to accomplish reducing the demand on one's parents, the participants in this study shared feelings of owning characteristics of advanced maturity, and exhibiting personal responsibility for their own wellbeing. This was displayed in both the sibling's behavior at the House while I worked there, as well as shared with me during our conversations for the current research. For example, even though it was against the House resident rules, most all of the participants were trusted to stay at the temporary residence unsupervised while the parents visited their sick child in the hospital. I believe it was assumed by the parents that in their absence the children were kept occupied inside the House by attending the Education Program, doing crafts with the fellow housemates or staying in the family's bedroom.

Another example of attempting to reduce the amount of stress or pressure felt by parents was the sibling's ability to suppress expressing their own academic needs for the greater good of the family. With the exclusion of Ali, all of the children adopted either a laissez-faire attitude or makeshift approach toward their own academic and personal development while displaced. Individual attempts, as outlined in Chapter 4, ranged from home schooling, enrollment in a public or private school system temporarily in Alberta, utilizing the Education Program at the House and studying independently to support one's education. The children came to rely most heavily on the Education Program while living at the residence. Regardless of the route to educational attainment, however, the children did not express high expectations of any one institution or their personal achievement capabilities. I believe, whether intentional or not, the relaxed approach of a non-traditional education program offered within the House provided the children an additional means of alleviating parental stress; parents were familiar with the environment and felt secure knowing that if they left their children throughout the day, there was at least a classroom or craft room for the children to be occupied by. They trusted that the children would likely be under the watch of an adult. This assumption was affirmed by Brianne when she was asked if she believed it was beneficial to her family to have an academic program at the House. She stated, "*it helped my family cause when they had to go to the hospital to see (her)… I could just stay there…and it helped me not fall behind in schoolwork".* Similarly, Dennis said that while it wasn't mandatory to attend the House Education Program each day, the learning resource was helpful; "*we wouldn't have to (go)… but I had to go to school to finish my work!"* It should be noted that the children did not disparage or discount any one academic path from being able to sufficiently support their educative goals – the fact is that educational achievement was not on their radar; providing compassion and empathy to one's family and fellow House families reigned top of their list.

Supporting Other Children and Families

Due to one's age or experiences being around a sick sister or brother, most of the children recognized their special ability to communicate with and comfort other families as well as seriously ill children. The value of this active participation was realized by both Tom and Ali. When asked how she spent her time at the House, Ali shared her general approach to interacting with other families recognizing her ability to play an important role in the lives of other resident children;

> *It was mostly just trying to find things (to do) and trying to keep everyone happy. Especially the kids who didn't understand fully. You just, everyone worked together to try to make it a happy place…and I would carry that attitude right to the hospital. And like, I tried to include all the other sick kids too. Like, you all work together to make everyone feel better and distract them… you create your own family there. Like, I was the only sibling there full time so, like, if there was a younger kid I would kind of adopt them as an older supportive sister kind of thing.*

By assigning herself the role of 'older sister' to other children staying at the House, Ali recognized this as partially out of her sense of duty but also because of her unique understanding of what other children staying in the residence were going through. Similarly, Tom was able to clearly place a process of his identity formation in the context of helping those around him, specifically other sick children. In the following excerpt from our conversation, Tom told the story of getting to know a sick child in the hospital and described the benefits to both parties for having made those efforts:

> *The one thing that really got me was this kid... And he was giving up and he knew he was dying and he knew what was happening and he was giving up literally. When I met him, he didn't want to talk to me, he didn't want to see me, he didn't want anyone to see him. He had a hard time with nurses coming in to see him. He, I can't say this for sure but… I feel like he was just like, 'I'm done. I want to die. There's nothing left for me to live for'. But, like, it's like that with my sister! So I went to (him) every single day and every day that I went there, I realized a change in him. Even when we weren't at the hospital, and we were just at (the House) for the day, I would walk to the hospital to go see him. And I really felt like I was making a difference in his life. And he's motivated me so much... It wasn't so much that I was proud of what I had done, it had opened my eyes to see, like, even the little things you do, like just going to see a guy… even though I enjoyed going to see him, I have never had a barrier between talking to people no matter what they're like. There's just never been a barrier between me and them. So, going to see him every day, I*

> *didn't feel like I was doing anything at the time. I would go in there, show him something cool on the ipad, show him a couple youtube videos or something, right? But it realized in me that something so little like that can have the biggest impact that you don't see and you hear it all the time. You hear people say, 'the little things count' and 'there's no small jobs', and 'you do this and it has big repercussions'. But you never really see that or feel that until you do something like that. Like, at the time I just thought I was going in there and having fun and making him smile and laugh. I thought, 'good, this kid needs some happiness'. But I didn't realize that it would go to the extent where he, he's like a brother to me, right? You think you have it so bad but then you see what other people are going through, and then they see what you're going through! And so (he) is going through hard stuff and I can relate to him even though I have never been through anything like that as an individual but I can relate because I can see it, right?*

Alternately, where the children did not recognize their own efforts or the benefits of their interactions with their fellow House mates, they were able to identify having benefited themselves from the outreach of others. When the question of how the House had helped him and his family, Jason said, "*friends… the comfort of other people supporting us*". Similarly, Dennis echoed the way each of the participants viewed living at the facility. It provided him with vital relationships with other siblings of sick children and served to remind him that his family was not alone in this struggle; "*my friends were there, yeah. There were some people that had, like…there's medical conditions there… that their brothers and sisters had*".

The community forged at the House between families and staff, as shared by the participants, provided comfort during times of endless uncertainty. And the roles assumed by the children both in and out of that community serve to help the children develop another dimension to their respective identities and perceptions of worth. At a time when feelings of isolation from one's family and constants in their previous lives prior to illness are pervasive, finding friends, new "family" and a place of belonging can prove mandatory for the survival of the sibling children. These new establishments can also serve to ease the adverse effects felt in their academic lives as well.

Changes to Life and Learning

Digging deeper into the participant's personal feelings about attending school during a period of time when they were removed from the home school and community, each child clearly articulated how their education had been disrupted by illness. Participants spoke about once having full lives; enjoying close social linkages, and feeling safe in their familiar surroundings. They also shared that attaining an education was much easier and enjoyable before their lives were disrupted.

One of the most troubling academic aspects of being a sibling of a seriously ill child was reportedly the residual effects of being disconnected from a formal education program, institution and one's peers. Years after experiencing educative disengagement, Dennis, Jason, Tom and Ali all felt the effects in their social and academic lives. When the conversations were held in May 2013, each child told of how their academic and personal lives were impacted and of the gaps created in their knowledge formation due to the lack of continuity in the instruction. They expressed insecurities in their current academic abilities to learn and retain information.

Social Impacts

All of the children stated realizing that their social lives had suffered and that this positively correlated to one's position on both school and learning. When the children were asked to elaborate on their feelings, the importance of one's social connectivity to their overall level of educational enjoyment and fulfillment became undeniably apparent. This line of questioning proved to be the most difficult to this point for me in the inquiry process as the majority of the children displayed some amount of sadness or frustration reflecting on the way life once was. Dennis said the move had negatively impacted his level of happiness because he lost friends each time he attended and withdrew from a school. As we discussed the specifics of his situation, I asked if it was hard leaving his friends. Dennis, in his very soft voice, said "*yes*". Dennis' body language changed; his head tilted downward and he began to fidget, pulling his sleeves over his hands. I noticed Dennis' eyes were full of tears as he focused his gaze away from me to between the table in front of him and his grandma sitting across from him.

Ali discussed the impact of social disconnection to her overall educational experience. Originating from a very small town, she shared with me having the same close friends throughout her entire childhood. To Ali, social disconnection combined with the isolation she experienced living somewhat contained in the House proved to dismantle the student's larger capacity to learn and enjoy new surroundings. Ali stated,

> *with school comes your friends and I guess I have gone to school, the same school, my whole life and so it was kind of like a second home to me and having to leave that was weird. It just felt like there was no filler and I just felt I wasn't a part of anything if I didn't have a class.*

Ali's comment recognizes a void in her new existence without the ability to be a part of her academic community alongside her peers. This speaks to the amount of emphasis students place on their schooling and social lives as tools in identity development and personal concepts of citizenship.

While not all of the participants were as explicit as Ali, as I held conversations with the other children, the effects of this sort of disconnection from one's home school and ensuing impact on identity and sense of self, both positively and negatively, were revealed.

Re-Entry: Social Lives and New Identities. Frequently in conversation, the children shared feeling *different* in their home school and social circles upon re-entry. While many of them attributed this difference to circumstance and time passing, Ali had a unique way of framing her feelings around her personal identity development. I asked how she felt returning to school after being away for four months. She said,

> *It was weird, yeah, because I had…it was almost like a culture change from such a big city life because I live in such a small town. So it felt kind of like country people. I came back as a city girl. So they didn't know who I was and I didn't know who they were.*

Here too, Ali iterated another lasting dimension to being physically absent from one's home school. She, like several of the other children, was faced with learning and relearning academic information as well as trying to uncover where she now fit within the social worlds and larger community she once navigated. Ali's comment lends to the student's acknowledgment of self as an individual who is arguably different than the child she was once in that same community.

Academic Impacts

In considering the academic toll, the majority of children acknowledged receiving lower grades and/or falling behind their peers both during the period of time away from the home school and upon school re-entry. The children explained their lower grades as results of being counted absent by the home school, missing opportunities to turn in assignments or not receiving adequate and appropriate educational provision while residing in Alberta. To support this notion, when I inquired into if he felt his sister's health condition had negatively influenced his education, Jason stated, which I believe most of the participants agree with, *"I think it did, yeah. Since I missed a lot of, like, studies, and, I don't know…I just feel like I missed a lot of school and that lowered my education".*

An additional area of academic impact acknowledged as a product of accompanying the family on short notice was the interruption of a sibling's illness on one's ability to concentrate at school. Ali illustrated this saying,

> *It's just always being on your tippy toes and you're always thinking about it and it's kind of distracting… When you're always concentrating on something else, eventually you just want to, I don't know, you want to desensitize yourself to it almost. Cause all these other kids have pretty much perfect lives and you see them succeeding and you're just kind of like, well, this is kind of on my mind instead of school work.*

Conversely, Dennis said that engaging in schoolwork on a deeper level helped distract him from the severity of his sister's condition. The complication here is that disengagement from his home school without an established academic path to look forward to caused discontinuity in his engagement thus losing the one coping resource he so relied on. The input from both Ali and Dennis is important to listen to in considering the meaning the children attach to the act of doing school work and being present in learning environments; they are required for the children to sustain their education while removing them from the stress and preoccupations of life as they now live it.

Drawing comparisons between before and after his academic disruption, Jason said, "*(school) was pretty easy for me. I got really good grades. Nothing was that hard to be honest. It was pretty fun too since I had a lot of friends".* All of the students shared that the hindrances to learning they experienced were not isolated during their temporary disengagement. The effects are felt to this day in both social and academic pursuits.

Residual Knowledge Gaps. Years after their stay at the House, many of the participants shared feeling unprepared and uninformed in the classroom. They acknowledged that the time missed receiving important lessons alongside their peers had made them feel incapable, created gaps in their understanding of required curricular material and disadvantaged them academically in comparison to their classmates. I asked the children to describe how it felt to return to school in one's home community after being in Alberta for months straight. Dennis' response was, "*I would feel different…just the lessons felt different*". I probed further, "would you feel behind?" Dennis confirmed my suspicion. Ali and Tom had additional complexities to account for in considering the lack of continuity in their learning. Both Ali and Tom resided permanently in another province where the students told me the timing of lessons was quite different than that of Alberta's public education system's curricular delivery. Ali said that she viewed her time attending school in Alberta's public school system as redundant and a cause of large holes in her comprehension upon returning to her permanent school. She stated,

> *It was weird cause at the public school in (Alberta), I did the same semester that I did at my other school so I didn't learn anything new. And so I guess I'd missed five months of schooling when I got back so it was just like trying to figure out what I was supposed to be doing in all the classes…it was like I was supposed to know this but I have no idea how to do anything!*

Upon re-entering her regular school, Ali enrolled as a new student and felt required to jump into classes and navigate content that she did not believe she was equipped to address; *"I didn't have to catch up, I just had to assume things when learning which is really weird and causes you to not know anything".* Two years after returning home and being enrolled in her high school of origin, Ali described to me how she continues to struggle academically;

> *Just gaps. Lots of gaps… I felt like I got really behind… even now I can feel like a chunk of my education is missing. It's hard to learn things at such a high level when you've missed even the small things in younger grades leading into high school.*

Similarly, Tom expressed feeling the effects of being absent in school years later. He also discussed how missing significant amounts of school in the context of the classroom had hindered him;

> *I did miss quite a bit of grade seven and there's stuff that even to this day that it affects. Even two years later, right? It affects, cause (other students are) like, 'oh yeah, I remember when we did that', and I've never done it before! I know how to do it because I've done it in other scenarios or just seen someone else do it but I don't really know how to do it… I may understand completely what to do but I never fully can understand how.*

In Tom's opinion, missing significant amounts of classroom instruction had directly inhibited his ability to learn and retain information. He stated,

> *Math is the biggest one that it affected… I do ok in it but I always have a really big struggle with it. Every time we get a test or quiz, I have to take a re-quiz or re-test cause I can't get it done. It just doesn't stick. But it just makes it hard, right? Missing all of grade seven? Missing a lot of really important things.*

Adding another confusing dimension to Tom's situation, as identified by him, is the fact that he was also home schooled. Tom said that the curriculum was unpredictable, sometimes lessons were drawn up randomly and delivered sporadically. Here he shares an important insight into his reality receiving a makeshift education out of necessity;

> *(I was) home schooling with a totally different academic (plan). I learned maybe this part (motioning to a section of a book with his hands) and maybe (my classmates) aren't even at that yet, right? So maybe I know things that they don't know but they know a lot of things that I don't in math and all those subjects.*

With all of the trying circumstances creating barriers to continued learning in their past, the students were each able to make sense for themselves of why it was necessary at the time and why they each chose this path or came to embrace it as their significances shifted.

Changing Priorities

It was important. I did not want to get behind, I did not want to fail, I did not want to do anything like that but it wasn't your first priority (Tom, Interview).

The above quote from Tom speaks to a theme expressed by the oldest participants; both education and the social components of school are important but in the context of being in a new city for the care and treatment of a seriously ill sibling, the wellbeing of that child is placed above the pursuit of one's own achievements and desires. As Ali discussed the topic of being displaced in Alberta, I asked her to speak about being removed from her social network and school life. She provided a clear sense of missing social elements but affirmed, given the situation, new experiences lead to new perspectives and priorities;

> *Well it kind of feels like a rip off, right? Cause you're kind of missing out on everything happening at home but at the same time you gotta look at, my sister missed her whole childhood so I think I can handle that! But, it's definitely, there's a gap in friendships cause you weren't there, you know?*

Like Ali, Tom developed rather pragmatic understandings of this new reality. They recognized and agreed with common ideals of children in their situation being overburdened and assuming adult appropriate tasks but to that point, however, they added that because of the conditions of an exceptional situation and the subsequent adjustments, they are broadly relatable and more interpersonally skilled than their peers. They accepted their ability to be specialists in communicating with both children and adults and hold that ability as essential to their identity development. Tom and Ali shared feeling increasingly capable of contributing significantly to the lives of others and taking a community-minded approach to life and learning at the House. These youths translated their difficulties into personal tasks and responsibilities to others in and out of the House.

As we discuss how the children's priorities had shifted, it is essential to acknowledge that the two eldest participants exercised judgement in the determination to accompany the family to Alberta. Both Ali and Tom had the option of staying in their home communities with older siblings or friends of the family for a period of time. Considering academic research presented in Chapter 2 together with the opinions of the participants, it is suggested that the insistence of the sibling children to accompany the family speaks to possible fears: fear of being left out of family affairs and/or fear of not being able to contribute according to their determined roles (Craft, 1986; Wallinga & Reed, 1990; Hamama et al., 2008). The former is demonstrated by Tom who, when asked if he would have considered staying in his community, stated,

> *if I didn't go, I don't know, I wouldn't have liked that at all. My parents, most of the time, gave me an option to stay or go and I would choose to go every time because I wanted to be there and I wanted to know what was happening. I didn't want to have to wait til they could maybe phone me. I wanted to see what was happening and what it was like. I like to be there when things are happening.*

Ali's reasoning aligns with the latter. She shared her personal desire to support her sister through the good and bad times. Her quote also serves to reveal sibling apprehension of fear of potential disheartening or abandonment her sister may assume if she wasn't physically present. I asked Ali if she considered staying in the home community;

> *I don't think that would have been a good thing because, you know, you want to be there for seeing your sister be well again, right?...I wanted to see her when her skin had colour, when she didn't look half dead… cause that's what it was! Like, you want to be there and in a couple years she wouldn't be like, 'where were you? And why weren't you supporting it?' right?*

The desires of the children to stay physically present provides important information regarding the latitude provided to them to make important decisions about their futures and ultimately to the roles they can play. The House can be seen as helping the children along through this time by enabling families to live together in the temporary home, to establish important social connections and supplement their education under the guidance of an empathetic teacher. The children are also able to develop their identities in their new roles in this controlled and safe environment.

The House As Home and School

By every account, the House is viewed as an essential resource to families. As described in an earlier chapter, it is a necessary residential facility for out-of-town families and equally important to helping children through their academic pursuits in a non-formal but supportive space. As shared by the children, the House also played a significant role in combating the adverse effects associated with the isolation they consistently experienced. In the following sections, the children elaborate on their view of the House as both home and atypical learning environment.

Home is a Time, Not a Place

When I asked the children to speak about the House as a facility, its function and impact, each child shared feelings similar to Ali. She said,

> *So, the biggest thing about (the House) was that you got to hear other people's stories and you realized that you weren't really alone. Like, you're not the only person suffering, I guess. You got to hear other people's stories and you got to know that they're fighting the same. You can all be supportive of each other. It's like a big community circle of people. Like a supportive group.*

Ali's point builds off of Jason's comment addressed earlier which presents several overarching areas of significance to the research. During a time when sibling children literally experienced isolation from friends and family, the children felt the House provided a way of surrounding themselves with similarly challenged children, they felt normal in this environment alongside other children, and families were essentially gifted a support network should they wish to engage with others.

By all accounts, everyone benefited from the mutual sharing of stories, struggles and successes. Additionally, all participants recognized how the House delivered an affordable means of keeping family members close to one another and the importance of the educational program as a near mandatory source of academic support.

More than an Education Program

Participants in this study hailed from locations across Canada and carried varied educational backgrounds. With all of their differences, one commonality between them was their reliance on accessing educational support provided inside the House. Upon inquiry, because each participant had a means of measuring the House program against traditional schooling, they were all able to speak to the learning spaces and resources made available to support their academic pursuits. Analysis connected important themes about the pros and cons of learning at the House, as well as to the changing importance and role of education due to the illness of a sibling.

As presented, the education delivery followed a tutorial format meant to supplement and support the formal education children received from their schools of fulltime enrollment. The teacher regularly instructed children ranging from grade one through grade twelve simultaneously which lead to a one-on-one pedagogical practice. During the conversations, I asked for opinions about the alternate program delivery and classroom environment at the facility. Participants highlighted several significant points which appeared to differ based on age and educational exposure. Tom, Ali and Jason, the three eldest, focused their feedback on the teaching method and lack of continuity in their studies while Dennis and Brianne emphasized the missed social benefits of attending school and the ideal characteristics in an educator to this characteristically unique type of learner.

Speaking to the style of instruction at the House, participant feedback was generally positive and in favour of the one-on-one instructional approach. Ali stated, attending the Education Program, she was able to supplement her education sufficiently in the informal learning environment;

> *I would get some schoolwork done but it wasn't like I was actually going to school. I would just be doing homework that I would have over the course of*

> *five months. So it would get me enough to pass but I wasn't actually doing school.*

Ali added that in addition to receiving tutoring for her studies, she and the teacher had a mutual passion for art. She was thus able to focus in on art as both interest and outlet under the teacher's direction. As a result, she felt that her artwork improved greatly because of the intimate time spent together. This focus was spotlighted by Ali as one of her few notable educational improvements uniquely possible through this program and during this particular period of time.

Tom recognized the instruction to be similar to that of home schooling which he received from his mother in grade eight. In this direct quote, Tom speaks to the classroom atmosphere and shifted the conversation to consider the strengths of the role of teacher in this environment. He said,

> *It was like in a class, right? So it was really cool in that way. When you went to the school there, it was nice cause there was only, like, two or three people there at a time... So, I always got a lot of attention if I ever needed the extra help. It was more, like, doing it at home. And the teacher wasn't really a teacher in a sense, the way you viewed her cause she didn't just do the teaching. So it was more of, like, a friend, right?*

Here, Tom draws attention to the benefits of learning in small groups and in non-formal places. He also speaks to the unique ability of the teacher in unconventional academic locations to connect with students on multiple levels – as both respected practitioner in a classroom and as a recreation leader directing crafts for the children outside of the learning centre.

The importance of the instructional environment and social aspects of learning between teacher to student and student to student relationships were prevalent in responses from the youngest of the research group. I asked the children to share their favorite parts of learning at the House. Dennis said, "*It wasn't that loud and… I knew the people around me… there weren't that (many) people and so I wouldn't be confused about the people around me"*. Dennis' heightened awareness of the potential to feel discomfort in his surroundings and with the people in his presence serves to remind me that policy pertaining to temporary residents requires great consideration when conceptualizing how to best serve students like Dennis in regards to appropriate environment, and pedagogy. Mindfulness must be maintained when building the academic and social environments created for these youths. As evident here, hailing from a variety of cultural and geographic backgrounds guides perceptions of security and general wellbeing as students attempt to learn and forge friendships.

To provide further comparison, when probed about what was important in a learning environment for students experiencing frequent exits and re-entries into a school, Dennis stated that it would be beneficial if students in the temporary school would be willing to make friends and the teachers to be nice. Brianne too described the interpersonal aspects of the House teacher as what made the learning environment so accessible and encouraging for her. This section discussion is elaborated on and carried into the next chapter where merits of non-formal learning spaces such as the House are examined further.

While the children discuss the importance of teacher aided new friendship in their temporary environment, emphasis equally remained on the connection with friendships back home. To help facilitate the maintenance of these connections as well as connections to the classroom, the students leaned on modern technology.

Role and Uses of Technology

A constant throughout conversations with the children was the usefulness of technology in maintaining a level of academic and social connectivity. Participants shared proficiently utilizing a variety of online and offline programs and devices. Additionally, all of the children spoke of the institutionalization of technology as a key component to the whole family's approach to connectivity and communication with employers, extended family and friends in the home community. Considering the academic and social goals of the children, technology proved essential.

Academic Support

Teachers in home communities reportedly provided lessons to students regularly using resources such as email or fax. Lessons were sent to the attention of the parents, students or temporary teacher and served to assist the students in staying up-to-date with their peers and provincial curriculum. Periodically, as shared by

Brianne, educators in the home school arranged with the House teacher for the sibling student to teleconference with classmates back home so as to maintain a link between children and the child to teacher (Brianne, Interview). Maintaining this line of communication between the children may also serve to help the child's classmates understand why the student was absent from school as well as assist with the child's process of re-entry back into the classroom and social networks.

Children receiving academic support at the House were also given access to laptop computers in the classroom and desktop computers in the family's suite. When available, the children could reserve laptop computers to use. The option to access technology was an invaluable offering from the House to the children as having this resource provided a means for the children to perform class work both in and outside of the instructional hours at the House as well as in non-formal spaces such as the hospital; an important consideration given the unpredictability of the family's schedule each day.

Social Connectivity

In the past ten years, with the introduction of programs such as text messaging, Facebook, FaceTime and Skype, social connections are easier to maintain than ever before. Online programs played primary roles in helping friends and family remain up-to-date on each other's life events. Surprisingly, when asked about the role of technology pertaining to their ability to maintain healthy communication lines to peers, only the three youngest participants shared relying on these tools. Both Tom and Ali said that, while the tools can be useful to some people, their friends either didn't have a phone, it was too expensive to speak on the phone or their friends did not utilize social networking programs. Brianne sporadically used video conferencing tools Facetime and Skype, while Dennis and Jason used Facebook to send messages to friends and play video games, speaking to friends while playing the games online, about once a week. The use of technology for the purposes of social connectivity cannot be understated here. With many travel hours between the children's temporary home and that of where their friends and family are in the permanent home community, communicating with the help of technology provided the students with an essence of 'home' and vehicle for speaking and seeing key people exclusively able to lend support and encouragement.

Chapter Summary

The data presented in this chapter serves to reveal the common points that siblings of seriously ill children perceive as lived and experienced, for better or worse, due to their removal from their home schools and communities. The student's narratives presented are essential pieces of knowledge when considering the complex journey travelled by students such as those in the current study.

While each child acknowledged the necessity of temporary housing to remain in close proximity to an ill sister or brother, participant narratives suggest it is a complex web of factors that cause significant short and long term friction. The student's emphasis on being physically absent from an academic institution, and social disconnection combined with the instability of their educational paths selected during the course of time in Alberta served to challenge and disadvantage the children. Easing the tensions, however, were factors such as moments to connect to the teacher on academic and personal pursuits, an intimate learning setting, the friendships developed and the technological tools provided to students.

Using a children's rights lens, the following chapter engages further into the discussion of the educational perspectives and schooling journeys of this group of students in an effort to address the research puzzle: what are the educational and school perspectives of the siblings of seriously ill children when required to travel for medical care? To understand the research puzzle further, the following chapter considers how we can understand the meanings formulated as drawn from experience, the rights of the children in Alberta, how to create room for their participation in policy, what the importance of the child's narrative is in the larger educational landscape and how to provide equitable and appropriate education programming for children uniquely challenged.

CHAPTER 6: DISCUSSION

From listening to the participants and performing a review of prominent literature, we know that the children in this research study are each invisible to the system. Their realities are not considered in academic research and their educative and social needs are not reflected in education policy or practice. This fact is not lost on the children and their families. In fact, the majority of the students wished to participate in the current study, in large part, to provide their insights and perspectives so as to be counted. All of the parents, in deciding whether their child should participate, considered the potential influence of revealing their circumstances as a key determinant. I believe the data that surfaced and is presented here through the children's recollections, stories and feelings can contribute to ignite larger conversations than either they or I could imagine. But first we must give them the floor.

We must not only inquire into and document the perspectives of the student, we must also attempt to understand their contributions to apply them in policy and practice. In the following Chapter, I consider the defined rights of the temporary resident student in Alberta against the needs of these students. The research goes on to ask, with what is presented here and now known about the circumstances and difficulties of being the sibling to a child will a serious illness, how can this knowledge affect education discourse and policy? How may the system respond to the needs of these students? And how do we meet the children where they are instead of the children wading through a system to achieve a full education? To address the final question, I present the merits of expanding the definition of "education" to include the intelligence gained through informal interactions and I explore the importance of non-formal learning spaces such as the House to uniquely challenged students.

The Child's Rights vs The Child's Needs

I support the notion that for change to occur, we must invite the voices of the people at the heart of the issue to participate in research, policy formation and development of pedagogical practices. The children's rights theoretical lens removes the possibility of talking around or about those who are directly affected by placing the child at the center of conversation. Examining the data using this framework allows for consideration of the meanings children attach to their narratives to be applied against the disconnection that exists between what the students need and what is actually made available to them. It allows the research to ask: what are the priorities of the children at this time? Considering how the children have shifted their emphasis away from education to focus on the wellbeing of the family, how can a democratic system come to invite participation from the children in question? What is required to provide them with an equitable and appropriate education given what we know about their individual and familial conditions?

To address these questions, the discussion must begin with an iteration of the child's adapting priorities and incorporate governing documents and Acts including: The United Nations Convention on the Rights of the Child (CRC) (1989), Declaration of the Rights of the Child (1959) and Alberta's School Act (1988).

Adjusting Priority

Tom provides very important insight into the sibling's new priority structure. He safely speaks for the other children in describing how socialization in his temporary environment was placed above that of education. What was once the crux upon which every aspect of his life rested, attending school and pursing an education are understandably pushed down his list. I asked how his view of education and school had changed since his sister's conditions demanded his attention. Tom said,

> *It was really more, 'do what you can do but it isn't your number one priority'. It's like, 'get it done if you can'. It's not… it's like, third in priority, right? You want to get good at (the topic) cause when you get back you got tests. You don't want to be behind. That's the worst thing you can do is get really far behind cause catching up is hard. So you don't want to get behind but it just kind of becomes back here (he motions behind his body with his hands to signify schools reduced significance in light of the situation) in priority level. It's like, 'ok, I'm going to do it but THIS is way more important, right? What's going on at the hospital.' And it's not even just in your family. It's important to connect with other people, right? So it's, it kinda goes back in priority. It isn't the biggest thing.*

Tom was assertive in defining his top three priorities in this order: supporting his sister and family, supporting and socializing with other families, his scholastic pursuits. This awareness begs the system to consider the challenges of students like Tom and the meanings they attach to learning conventions. They represent temporary residents to Alberta who cannot predictably attend public schools due to circumstances out of the family's control.

Like Tom, the other children in this study were very clear on the details of their education and school journeys. By listening to them we can take valuable information from their narratives: they are not reflected in education policy or Alberta Public School practices, their circumstances require a repurposing or redefinition of both 'school' and 'education' to suit their priority structure and their experiences provide specific insights into special provisions necessary to support the uniquely challenged and temporary resident student.

Status Within to the System

The children tell us that they are not reflected in policy. They recognize that they are individually challenged, even within the same family, and that no one educational system or board has been willing to support their learning and development fully during this time despite their pleas and efforts. This is reinforced by the fact that between the five children, a large variety of attempts were made to achieve academic continuity both with success and failure: home-schooling, utilizing the House Education Program, attending the Hospital Specialized Public School, general public school, private school, and independent learning supported by one's home school. Further, the children point out that because they are not acknowledged by education governing bodies and systems, there are no suitable identified paths to achieve academic continuousness and success. To this point, no two children other than brothers Jason and Dennis pursued education attainment alike. This is in part because duration of stay varies by family but also because they are not aware of appropriate learning options. Such options require consideration of the need for a controlled learning environment to reduce risks of contracting viruses or infections that may be transferred, the unpredictability of one's attendance, special social needs of the children, the imperative of children's given roles separate of student and the need to coordinate or communicate with one's home school to support re-entry.

In response to their declared needs and altered academic perspectives, I look to the official governing documents which dictate entitlements and rights of the child in Canada. The following section reveals rulings of the Declaration of the Rights of the Child (1959), United Nations Convention on the Rights of the Child (CRC) (1989), and the Alberta's School Act (1988) to continue the discussion.

International Rulings

The Declaration of the Rights of the Child (1959) formed the basis for the CRC, established thirty years later in 1989. The Declaration (1959) plainly states "mankind owes to the child the best it has to give" leading the reader to Principle 2 which claims,

> The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration (Declaration of the Rights of the Child, Principle 2, 1959).

Since its inception, the CRC (1989) has been the leading voice on children's rights internationally. Canada, as a signed member, is officially required to comply with the rulings as detailed in the document. Particular to the current study are Articles 3 and 28 of the CRC. Article 3 echoes the special consideration provided to children stating,

> In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration (CRC, 1989, Article 3(1)).

Unfortunately, neither the Declaration of the Rights of the Child (1959) nor the CRC (1989) apply wholly to the demographic depicted in the current study entirely. There is tremendous subjectivity in the rulings of both guiding documents for a couple reasons. The lack of clarity around particular terms such as "normal" and "best interests" poses an issue to those seeking information. As well, the rights stated in the CRC differ in their ability to serve. Robin Mama (2010) explains that some rights are *aspirational* or yet to be achieved – "realized to the maximum extent of (each nation's) available resources" (p. 180). Other rights are *conditional* – they "rely on evolving capacities of the child" (Mama, 2010, p. 180). And shared rights are those split between parents and child (Mama, 2010). These classifications of rights leave room for debate around the intention of the Convention and applicability on the local level. Article 28, specifically addressing the education rights of the child, says,

> Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity… Take measures to encourage regular attendance at schools (CRC, 1989, Article 28(5)).

Again here, who determines a "regular" amount of attendance? Based on the children's stories, since attendance in the House Education Plan was not officially accounted for typically, they were not attending school on a scale nearly that of which could considered "regular". These bills were developed on a global platform – one must assume more tactile, audience specific and narrowly formed policies are made on the provincial level for the purpose of the betterment of all.

Provincial Rulings

The official governing policies, while attempting to be both broad in scope and inclusive, unfortunately appear to remove children with exceptional circumstances and temporary residency status from the conversation about their rights. The space between policy and practice is created through the lack of detail in these documents. Acknowledging the impossibility of including every circumstance in the Acts and articles, the fact remains the same; the children's needs are not being met as either permanent resident in their school of enrollment or as temporary resident in Alberta and therefore they are not supported sufficiently.

In Canada, each province is responsible for providing education. In Alberta specifically, education policies and procedures are outlined in the School Act (1988). The Act provides legislation about students, teachers, schools, governance, etc. Per the Act (1988), in Alberta, "temporary resident" is defined under the guidelines to

Section 8. The Alberta's School Act (1988) gives all temporary resident students full access to a public education program (s. 8). Transfixing the issue, just as with the Declaration of the Rights of the Child (1959) and the CRC (1989), is the lack of clarity around key terms and determinations. Particularly, the Act (1988) is not clear as to whether this declaration includes the child's right to an *appropriate* and *equitable* education when unusual circumstances are a factor.

To answer the question of what is appropriate or what is an equitable education, we can look to the children's scenarios as shared for initial guidance. We know from their testimonials that as temporary residents in Alberta, the students are not easily integrated into public systems and suffer friction at every stop along their journey. That considered, the children assign significant value to attending school. As shared by Ali previously, some participants position going to school and achieving an education as means to feeling like normal students alongside peers, and as social and creative outlets. Therefore, an appropriate education considers the constraints placed on the children, the other identities of the child and how to make room for the many selves while realizing attention is not on achievement alone.

All of these terms taken together pose problems for the institutions and practitioners assigned to temporarily support the student. It is a complicated scenario the children find themselves in but I believe sourcing an equitable and appropriate education should not be added to their list of tasks during this time. What are presented as the prerogatives of the temporary resident student in Alberta are arguably insufficient given what we know about this group and what the system is not positioned to provide. The issues of equity and appropriateness are discussed further in the following section as influencing discourse is considered.

Influencing Discourse and Practice

> If students come to school in unequal circumstances, they will largely, though not entirely, leave schools with unequal skills and abilities, in both cognitive and non-cognitive domains. This is not a reason for educators to throw up their hands (Rothstein, 2004, p.129).

The children are uniquely positioned to improve upon education policy, thus improving program delivery and pedagogy. To act upon this opportunity, it is important that children’s ideas and comprehensions are reflected in academic research. Policy level consideration can only be achieved by embracing a justly democratic system and acknowledging children as right-holding citizens regardless of province of origin and familial conditions. The policy issues that concern them are supported by the CRC (1989), Article 12:

> 1. Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child;
> 2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative.

Article 12 makes two very distinct assertions on behalf of the child which opens the conversation to those who question whether children know what is best for them. Mama (2010) argues that if children are accorded human dignity through the demonstration of their human rights, then they have the right to be listened to and play a decision making role to their own future. The author also states that through engagement with these rights, children are better prepared for an active role in society (Mama, 2010). These terms and goals of the CRC should not change when a child becomes a temporary resident with unavoidable academic and social hurdles.

The children here are identifiable due to circumstance but they are far from unique. With the House serving approximately a thousand families annually, we can be certain that a significant portion of those families across the country find themselves similarly challenged each year. With so many children likely experiencing similar difficulties to achieve academic support, the research calls for consideration of the child’s need for an appropriate education. What is an “appropriate” education beyond a basic right of access? The following sections address this question through dissection of education equity, revisiting what is “educational”, considering alternative learning spaces and teacher support of temporary students.

An Equitable Education

There are many factors to anticipate in thinking about how to best reach academically at risk youths. Participation in decision making is essential, as outlined above, but beyond that we must drill down to the specific inhibitors and areas of immediate address. Policy makers and practitioners must be mindful that not only do the children here juggle complex familial strains, they are also vulnerable to poor adjustment outcomes and demonstrating psychosocial difficulties such as emotional disturbances (Bellin & Kovacs, 2006). Taken together with serious consideration of the meanings within their stories, we come to see specific areas of institutional underservice or even disservice. Two referenced in the previous section as made apparent by the students are education equity and appropriateness.

The term equity is frequently used in policy documents but rarely defined. The standard definition of equity is “the quality of being equal and fair” and “that which is fair and right” (Oxford English Dictionary, n.d.). There are two dimensions at work in defining equity in the context of education: fairness and inclusion (The Organisation for Economic Co-operation and Development, 2008). Fairness lends itself to ensure personal and social circumstances do not restrict one’s ability to achieve academic success while inclusion refers to “ensuring a basic minimum standard of education for all” (The Organisation for Economic Co-operation and Development, http://www.oecd.org/edu/school/39989494.pdf).

As we consider the children reflected in the current study against this definition of education equity, I am challenged to assume they are recipients of either a fair or inclusive education when their circumstances shift. The data in this study reveals the fact that personal circumstances do restrict the student’s ability to achieve which goes largely unaddressed. For example, only in the last decade has research revealed that siblings of youths with particular disorders “exhibit greater conduct and academic difficulties than peer comparisons” while siblings of youths with diabetes “report lower self-esteem and more depressive symptomology” than children with healthy siblings (Bellin & Kovacs, 2006, p. 211). As a vulnerable collective, I argue that part of providing an equitable education means addressing the emotional needs alongside academic goals. Fostering resilience in the youth and identity development are ways of doing so. This approach calls for enhancing individual-level protective qualities such as communication skills, self-esteem and overall sociability (Bellin & Kovacs, 2006). To the point of socialization, brothers, Jason and Dennis inform that integration into a class academically and socially is not easily achieved. Within a school setting, this form of exclusion can be quite troubling to youths. Bellin and Kovacs (2006) hold that schools must assist these children by reinforcing a child's self-esteem, self-efficacy and the fostering of connections.

Threatening disservice to attainment of an equitable education is the fact that once a child becomes disengaged from their school of origin, their student classification changes within the system. For the period of time required to leave at a moment's notice, the child is no longer a typically developing student capable of attending school and receiving its many benefits on a predictable Monday through Friday schedule. Based on this point and on the data reflected in the study, students who travel with the family cannot be serviced in the same ways that typically engaged students are. We must acknowledge this fact – these students require additional or different support during the times of mobility and upon re-entry into the home school to ensure a chance at personal, social and academic success. To meet the needs of these students and students like them, it is necessary to expand popular concepts of education delivery to ask how we can support these uniquely challenged students. Part of ensuring an equitable and appropriate education includes the knowledge base and empathy of teachers at the helm.

Reconceptualising *Education*

The students in the current study call for a revisiting of the definition of "education" and of what is "educational"? John Dewey's *Experience and Education* (1938) suggests education is more than what can be received in a traditional classroom. The scholar calls for consideration of a *progressive* or *new* education in which the natural connection between education and personal experience is recognized (Dewey, 1938). Dewey (1938) holds "acquaintance with the past may be translated into a potent instrumentality for dealing effectively with the future" (p. 23) and that every experience finds life in further experiences. This stated, Dewey (1938) clarifies that not all experiences are equally educative; experiences may also be miseducative leading to the stunting of rich experiences in the future. I hold alongside Dewey and the students in this study that an education can be received outside of traditional and predestined learning environments. We feel that what happens between people is also educational. To the imperative of inclusion of the sibling narrative for policy, curriculum development and pedagogical practice, Connelly and Clandinin (1988) speak of the entirety and richness of a sibling's experiences and perspectives. The scholars state (1988), "each child's whole life experiences, both in and out of school, need to be considered" (p. 27). Connelly and Clandinin (1988) argue that

> the idea of narrative as a story of life as a whole, combined with the notion of curriculum…means that we need to broaden our idea of education beyond that of schooling…It is true that some such experiences occur in school, but it is probably also true that many of the most important educational experiences in our narratives occur outside of school, for instance, in family relationships, births, deaths, and marriage. … Such experiences are educational (p. 27).

The authors illustrate that for the additional purposes of enriching the world of education and curricular development, expanding on the definition of what is "educational" to consider the learnings of the child in all possible environments is advised. By doing so, academia acknowledges the humanity of the child and the legitimacy of those character building events in life that cannot be taught in a classroom. Mama (2010) supports this call for expansion in alignment with Connelly and Clandinin (1988) stating the CRC starts from the premise that the family is the vehicle through which children learn and develop into individuals. Tom nicely illustrated this point when I asked him whether his sister's illness had positively or negatively affected his educational pursuits;

> *It has helped me in numerous ways. I don't think there's one thing it hasn't helped! …You're looking back at history cause you're looking all through, not only just like, the disease. Say you're wondering how she got it, right? But you're like, 'is there anyone else in my family who's had it?' and you're looking back at that. But the biggest thing that it helps you with for me personally is science. Cause you learn all about how the inner mechanisms of*

> *how your body works, right? And you learn things just from hearing the nurses and doctors talk. You're like, 'I wonder what that word means?', so you google it or something and you figure it out. It's really fun. And now you get back to school and we're dong biology and all those things… and I'm like, 'oh yeah, I know what that is!' and spit it out, right?! You have lots of spare time on your hands so anything that interests you, you can do. You can work on it, study it, right?*

The points of consideration presented here hinge on the need to make room in the curriculum for the *out of classroom* moments that inspire learning and support curiosity. It calls for a redefinition of the concept of 'education' to include these knowledges and meanings derived through experience. As well, the research calls into question the legitimacy of an educative landscape. The following section addresses the need to expand conceptions of legitimate learning as limited to specific places. I propose the House and a variety of spaces as successful examples of learning happening in alternative and non-formal locations.

Learning Spaces and Places

An additional area where investigation into participant narratives might influence systemic change is on the topic of learning spaces. The children inform the research to the fact that educational lessons do not always occur inside a formal institution. Through the telling of their stories, the children took the researcher through time and space to detail the fact that they require flexibility in the timing, location and method of pedagogical delivery to receive an equitable education to that of their peers. The children spoke of the importance, despite not always being convenient comparatively, of finding opportunities to perform the formal tasks of school work at the House and in the *in-between* spaces. In the following section, I use the term *in-between* to describe the windows of time allowing one to do schoolwork and the places which the children frequented which were often the only locations available to them to complete school work. These spaces included hospital hallways, waiting rooms, patient rooms, the family vehicle, the family suite at the House, and unofficial classrooms such as that at the Hospital and at the House.

In the research, the children tell of doing their homework when opportunity arose and in a variety of locations. Here, Tom describes what it was like fitting lessons into life;

> *Working in the hospitals just doesn't… you're like, 'ok I can sit and do it over in the waiting room but then say you're in one waiting room and you're doing it there but then you have to move over to a different waiting room for physiotherapy and you're moving around. So, it's really hard!*

Similarly, Jason shared that *in-between* appointments and while traveling to and from Alberta for his sister, he performed his homework in the car. While not ideal in any way, the children recognized that without an education system to support them, one must take advantage of these places and periods of time as their only means to academic success. This emphasizes the fact that siblings of seriously ill children require support to suit their lifestyle. Interestingly, through our conversations, all of the students in this study, regardless of age, presented an interesting fact about education systems throughout Canada; the child is required to come to where education is provided. Education does not come to meet the child where they are. And as depicted in the current chapter, when a child is isolated in a temporary city with a collection of adversities, they are forced to find education where they can as they travel as dictated by illness. In asking how to bring education and learning opportunities to the students, input from the students tells us that they learn in out-of-school locations, and they learn when opportunity and time allows them to when not at the House.

Having presented the House previously, the benefits of this facility are well known. However, the children pointed out independent of one another that learning in this non-formal landscape provided the ability of the students to enjoy more direct and uninterrupted instruction as they work during the periods of time available to them within an appropriate and conveniently located space. Receiving academic support in the House served to keep similarly challenged students together, reinforcing the social bonds forged outside of the classroom. Recognizing their isolation within the residence, away from friends and sometime their family, the children greatly appreciated learning alongside familiar faces and similarly challenged individuals.

Considering these arguments together, this section calls for consideration of expanding the ways and places we make learning opportunities available to students to be received and to engage in their learning. For equity to be possible, more out-of-school learning spaces must be actualized by governing bodies and policy at large. This may include providing access for children to learn within the hospitals from hospital school teachers, learning in facilities already equipped such as the House and identifying ways to support them when they must educate themselves independently. Meeting the children where they are in their learning landscape also means expanding the delivery of curriculum. To do this requires coordination between provincial jurisdictions. Children should not be left to learn alone while we wait to see the outcome of their unsupported efforts. If they are entitled to the bare minimum the public school system has to offer, the least they should receive is contact with an institution and practitioners to support their way of life and academic goals.

An Appropriate Teacher

As stated previously, the House plays a large role in providing instruction and resources to the students. Mandatory to the success of the House's Education Program was having an established and equipped school room. Paramount, however, to the delivery of an equitable education to the students was the placement of an informed and capable House educator. Given their vast collections of exposures to practitioners accrued as each made an effort for continuity, the children all felt their input here could contribute to determining the ways they, or temporary students like them, could be better supported. Their suggestions are drawn from the meanings the children attach to the purposes of learning and the importance of an informed instructor.

While the children held distinct concepts of an effective and appropriate teacher, each child recognized the role of empathy in the learning environment as a key element affecting peer and teacher – student relationships, learning abilities and identity development. Specifically, however, the youngest children in the study emphasized the importance of having a kind teacher sensitive to the familial circumstances. They also suggested the benefit of teacher facilitated friendships for temporary students to a new institution. Brianne emphasized the young student's preference to an intimate learning environment in order to feel comfortable enough to even begin to build a trusting relationship with an educator. And for Tom, the most important role the educator could play was to the implementation of structure and predictability in each student's day. Tom's perspective on this topic is of interesting significance as he was the only student to receive homeschooling where there was little structure in his experience. This can be understood as his ability to recognize the best methods and conditions for learning in his opinion separate of his reality. Differently, Ali spoke to the tactile intelligence required of teachers;

> *You need a special teacher, I guess. Maybe someone that's educated about the problems and emotions that the kids are going through…you don't want extra stress I guess at that school so it's good to create the atmosphere of comfortable learning.*

Ali summarized the children's collective statements beautifully in this quote. As an eldest sibling in the House, she articulated the appropriateness of placing a patient, informed and empathetic teacher within the environment of siblings of seriously ill children to maximize their potential. As witness, I can attest to the fact that the House employed two such practitioners to lead the children; both of which embodied the children's descriptions of an ideal teacher. This speaks to the fact that the children used their ability to weigh the qualities of practitioners between institutions to attach key attributes to those aspects seen as either helping or hindering their education.

Placing an appropriately knowledgeable practitioner in the classroom with siblings of sick children is essential to the child's success and a large component of an equitable education. As the children added, the bond they forge with the instructor was like that of a friend as much as a teacher. This is evidenced by the role I provided the House teacher in the current study. I included the teacher in all of the face-to-face and online introductory discussions with the children and their families as a means of gaining their trust in the process and trust in the researcher through association. I doubt the children would have engaged with me as openly as they did without the blessing of their teacher.

Chapter Summary

By simply listening and acknowledging student voice, improvements can be made upon the learning resources available to support them and in turn, improving their overall quality of life. And as full right-holding citizens, they are entitled to the same equal education as their more consistent peers. It is stated here, however, that additional considerations are required to ensure the equity of their education is assured as the child's attention is refocused on the status and health of the family unit.

At the foundation of the conversation is the fact that at all costs, children want to remain with their family. As students deemed sufficiently mature, it is their right per the Alberta's School Act (School Act (s. 1)). Considering this, it is incumbent upon education boards, districts and practitioners to evolve with the students and to meet the children where they are. Policy must consider the individual circumstances of the family which force typical students to become uniquely challenged students. In the following chapter, I summarize the research and elaborate on the discussion started here by making recommendations for further action.

CHAPTER 7: OVERVIEW OF THE STUDY AND RECOMMENDATIONS

Overview of the Study

Each year, in Alberta alone, upwards of a thousand school age siblings of sick children are educationally disadvantaged by no doing of their own. As the sister or brother of a child requiring specialized medical care temporarily in a new city or province, the students in question spent days, weeks, even years displaced. The current study brought the children's issues to the fore so as to consider the complexity of their realities as the children each perceive and understand them. In doing so, this study addresses the research puzzle as stated; to explore the educational and school experiences of the siblings of seriously ill children required to travel for treatment. Through this investigation, the study shows that illness in the family affects everyone and it is through the children's recollections and meaning making that we see how their relationship with education and school is affected once illness strikes.

A review of literature presented both dangers and benefits to the emotional, social, and psychological state of the sibling child. Scholars' findings stress how redefining familial roles can cause significant stress and isolation to well child(ren) in the family (Barr et al., 2008; Bellin et al., 2006; Healthychildren.org, 2013). This is reportedly compounded by the fact that the special needs of this group of students are unnoticed by most adults including the parents. Additionally, it is theorized that the expectation from parents and the child(ren) themselves to perform adult appropriate tasks, sometimes beyond their capacity, may impose additional stress and possibly prevent the child's full identity development. Alternatively, it is shown that having a family member with a chronic health condition does not sentence well children to poor outcomes. Participants and adults in the research reviewed described how healthy children may grow positively during difficult ordeals. Areas of potential growth include increased empathy, appreciation for one's own health, advanced communication skills, patience and identity development through agency. The children in the literature (and current study) acknowledged that despite sometimes being able to choose their path, many conditions of their lives have been dictated to them by the illness of a sibling. As a result the children shared feeling uniquely equipped, beyond that of their peers, to confront adversity. These attributes were held by children as essential to their personal and social development.

Considering education and schooling themes in academic texts, it is evident that limited scholarly work focused on educational implications currently exists. Of the research available, emphasis is placed on the connection between increased stress and frequent mobility to one's school attendance. As well, issues of educational discontinuity and insufficient institutional support are thought to make vulnerable and disadvantaged children. Findings, as presented in the review, call for this group of students to be specially supported in practice and reflected in policy explicitly. To accomplish this, the research draws attention to the importance of helping children understand the circumstances that lead their sibling to fall ill and to assist them in realizing that they are not expected to keep their feelings, thoughts and fears to themselves throughout trying ordeals. Additionally, children must be moved to the centre of the conversation and be directly included in it; the current study aimed to do just that.

Engaging the children themselves required creating a space for their voices to be heard and realized in the research. This was made possible through the narrative inquiry methodology in which the children were placed at the heart of the conversation about their experiences. The children and I spoke both conversationally and formally, guided by an interview key, to explore the perceptions of the youths pertaining to their educative journeys and relationship with school. Narrative inquiry served to strengthen the participant – inquirer connection by using tools such as memory boxes, joint recollection of shared experiences and through the inclusion of the House teacher in our conversations. Additionally, through the process of inquiring, I was able to locate myself in the research. I uncovered similar educational disengagements from my youth to that of the students and similarly held philosophies on education and learning as a result. Together, we were able to identify these underlying connections to each other as significant to the study. Equally essential, however, was the fact that engaging the children narratively helped move the research beyond the deficit-laden perspective, which I approached the study with, to realize the presence of a growth-enhancing, resilience lens.

As the students and I engaged in the inquiry process, their memories, thoughts and feelings revealed key understandings of experience. Following conversations and data collection, field notes and interview transcriptions were poured over. From this, many interesting and important themes surfaced of the children's comprehensions and meanings of methods of learning, and roles of people and environments. Revealed throughout was the fact that each family in the study struggled to balance new demands of life: attaining the best medical treatment for the ill child, caring or finding care for the well child(ren), navigating systems in a foreign city or province, maintaining employment to provide for the family and meeting the parents' need to care for themselves. To ease the burden, families relied on family, friends, services for temporary residents (such as the public school system) and facilities like the House. Established to lessen the stress of families with an ill child, the House was believed by each child to assist in keeping families intact, provide families with more time to be with the ill child, to allow for easy access to the ill child due to proximity to the hospital, access amenities required for comfortable living, enter a community of similarly challenged families and receive support for the educational and social pursuits of the youth.

The students shared their visions of changing priorities. Each student identified themselves as responsible to varying degrees for providing care to the ill child, alleviating parental burden and supporting other families staying at the House. The children's identity as source of support or caretaker was held as paramount to all other identities they may possess. Caring for one's ill sibling included maintaining a positive attitude, acting 'normal' in their presence, researching alternative medical treatments and performing actual lifesaving tasks when required. Support for parents included accepting some responsibility for the wellbeing of younger family members, requiring little attention from parents and suppressing desires typical to children/students. In terms of assisting other families in similar situations, the children recognized the value of the advanced abilities to communicate with all varieties of people: young, old, ill, and well. From the children's points of view, performing these tasks and being selfless were embraced as short term and nonnegotiable functions at the cost of the child’s own academic, social and emotional wellbeing.

In speaking about the roles of school and learning, the children recognized missing important experiences and lessons alongside classmates. At the same time, however, each understood both to become appropriately altered once faced with being removed from one’s home and familial distress. Academic abilities were considerably compromised by issues of recurrent and unsupported re/entry into schools, limited communication between practitioners in different locations, and systemic inflexibility to consider the unique facts of their lives which made traditional learning near impossible. Added, the academic impacts reported by the children included substantial residual knowledge gaps that remain years after returning to one’s permanent institution. In speaking to alternative learning options, the House Education Program was viewed as a necessary resource, allowing children to receive one-on-one instruction from a compassionate teacher while keeping them in a controlled environment with similarly challenged students and friends. Socially, the majority of the children shared feelings of sadness and isolation in discussing school friendships, describing them as missed, lost and/or elusive.

While at times helpful, modern technology was not reportedly sufficient in supporting learning or friendships challenged with distance and circumstance. Academic support via online tools was reportedly received by way of sending and receiving assignments between permanent and temporary schools via email or fax. However helpful, this was sporadic and underutilized by practitioners. Ultimately, friendship as a concept evolved for each of child; once gained and cultivated with children of a similar age in association with learning environments and location, friendship became something grown between similarly challenged individuals of all ages in a supportive network (such as between families staying at the House or frequenting the hospital).

Interrogating the data further to better understand the realities of these youths required a comparison of the child’s rights as student and temporary resident in Alberta against the needs of the child faced with academic, social and familial complications. Knowing each child’s priority shift away from formal education toward learning organically within one’s immediate surroundings, the analysis that resulted proved to reveal the barriers and opportunities to providing these students with an equitable and appropriate education. First, their needs are unmet between permanent and temporary schools. Once they exit the permanent home school, they feel relatively illegitimate to both school boards and institutions. Second, as temporary residents with special circumstances, there are no suitable routes presented to them to formal academic achievement. Third, while international and provincial governing bodies such as the Declaration of the Rights of the Child (1959) and Alberta’s School Act (1988) have determined each child, regardless of their place of residence, as having a right to access schooling appropriate to their needs and that all efforts should be made to provide this, they remain under and inequitably served. Despite clear knowledge of the risks of nearly a thousand temporary residents annually in Alberta, local administration has failed to execute on the stated goals of legislative bodies to support this group of learners appropriately.

Further, the children inform the research that an equitable education requires revisiting the definitions of educative spaces and places. While the children acknowledged the value of the formal learning environment, their reality calls policy and governing bodies to expand on those places believed to be appropriate and educative when one’s ability to access traditional schools is compromised. Further, the children reveal feelings of what makes an appropriate teacher; an important contribution to the discussion around their overall education experience and relationship with school and peers. Practitioner qualities of instructional flexibility, empathy, kindness and friendship are viewed as imperative to an equitable education.

Together the themes here position the research to request investigation into the issue of an equitable education for these students, acknowledging the child’s full citizenship and rights. As well, the study calls on education scholars and governing bodies to consider the essential institutional and pedagogical information the children possess derived from experiences and perceptions unique to only them. To truly understand these youths and pursue systemic change on their behalf, however, research must draw intelligence from the children themselves as specialists in the subject area and their testimonies considered within familial and social contexts.

Recommendations

As co-authors of the research, the participants and I put forth the following recommendations for policy, practice and research consideration:

Policy

- The process of policy development should create room for the experiences and perspectives of the siblings of seriously ill children to be incorporated ensuring their realities are reflected in policy and practice. To fully consider the complex reality of the child in policy, their circumstances and changing priorities must be realized.
    - While the children assert that being at the top of the class academically is of little importance in the face of serious illness, attending a school remains essential in a child's life.
- Revisit the concept of education equity and the associated supports granted to temporary residents of Alberta to provide an inclusive and full education based on the needs of the child.
- School Boards across provinces must collaborate. With students spanning the country accompanying the family unit, administrators and practitioners can share methods of providing a flexible and supportive education which works with the child's lifestyle and is easy for families to navigate.
- Consider counting attendance at alternative learning facilities currently providing education support such as the House. This may require assisting atypical learning places in attaining the status necessary to have attendance counted and to reside under an existing governing body.
- Curriculum should be developed to consider the multitude of knowledges, experiences and identities of the child, recognizing that learning occurs both in and outside of the classroom.

Pedagogy

- Teachers in both permanent and temporary schools should be required to collaborate in a predictable manner to support child(ren)'s re/entry into schools. This is of particular importance for those students temporarily residing in a different province with different timing of curricular delivery.

- For those working with siblings of seriously ill children, they should receive specialized training on the complex number of elements affecting the overall wellbeing of the sibling child. The children in this study inform the research that empathy and understanding of the social, emotional, familial and academic demands on the child need to be consider. The research calls for academic leaders and practitioners to be mindful of how a child's family may influence the day to day experiences of the child and the reciprocal nature of those influences.

Research

- The study calls for further research into the circumstances of the child and subsequent challenges to educational attainment to understand fully what it means to provide an equitable education to this population.
- Include the child in the research, recognizing their unique understandings derived from unique experiences.
- Conducting a longitudinal study on and with the siblings of seriously ill children to learn how these students are affected years after being withdrawn from their home schools and community for periods of time. Such a study may provide invaluable insights pertaining to identity and character development, the role and maintenance of friendship over time and academic achievement and/or weaknesses. This knowledge can inform policy makers and practitioners, creating opportunities for positive outcomes for similarly challenged families.

Final Thoughts

The recommendations presented here are based on the various experiences and associated meanings as shared by the child in this study. The suggestions were made possible through the use of the narrative inquiry methodology and in consideration of the rights of the child to an appropriate and equitable education as temporary residents in Alberta. The policy, practice and research recommendations all serve to position the child at the front of the research, asking academics, administrators and practitioners to recognize the child as specialist in the subject matter and exceptionally capable of providing essential knowledge required to improve upon existing policies and practices.

By acting on the recommendations above, it is possible to create space in research and policy to consider the competing demands of the sibling student's evolving priorities, identities and responsibilities against their educative needs and rights. Ultimately, the study requests that education and learning opportunities be brought to the child where they are and to recognize the validity of their alternative learnings and development opportunities outside of the classroom. This calls for specific teacher training, and large scale collaborations between institutions and practitioners spanning provinces. Together, the recommendations put forth maintain that attending to the individual strengths, capabilities, and needs of the affected youths is fundamental to helping children and their families successfully adjust to the ongoing and often unpredictable journey of childhood chronic conditions.

REFERENCES

Barr, J., Daniel, G., & McLeod, S. (2008). Siblings of children with speech impairment: Cavalry on the Hill. *Language, Speech & Hearing Services in Schools*, 39(1), 21-32. doi: 10.1044/0161-1461.

Bellin, M., & Kovacs, P. (2006). Fostering resilience in siblings of youths with a chronic health condition: a Review of the literature. *Healthy & Social Work*, 31(3), 209-216.

Bellin, M., Kovacs, P., & Sawin, K. (2008). Risk and protective influences in the lives of siblings of youth with spina bifida. *Health & Social* Work, 33(3), 199-209.

Bluebond-Langner, M. (1991). Living with cystic fibrosis: The well sibling's perspective. *Medical Anthropology Quarterly*, 5(2), 133-152.

Bruce, B., & Ritchie, J. (1990). Nurses' practices and perceptions of family-centered care. *Journal of Pediatric Nursing*, 12(4), 214–222. doi: 10.1016/S0882-5963(97)80004-8.

Chesler, M., Allswede, J., & Barbarin, O. (1991). Voices from the margin of the family: Siblings of children with cancer. *Journal of Psychosocial Oncology*, 9(4), 19-42.

Clandinin, D.J., & Connelly, F. M. (2000). Narrative inquiry: Experience and story in qualitative research. San Francisco, California: Jossey-Bass.

Connelly, F. M., & Clandinin, D. J. (1988). Teachers as curriculum planners: Narratives of experience. New York: Teachers College Press.

Connelly, F. M., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. Educational Research, 19(5), 2-14.

Convention on the Rights of the Child. (1989). United Nations. Retrieved from http://www.cirp.org/library/ethics/UN-convention/

Craft, M., Wyatt, N., & Sandell, B. (1985). Behavior and feeling changes in siblings of hospitalized children. *Clinical Pediatrics*, 24(7), 374-378.

Craft, M. (1986). Validation of responses reported by school-aged siblings of hospitalized children. *Children's Health Care,* 15(1), 6-13.

Declaration of the Rights of the Child. (1959). Retrieved from http://www.cirp.org/library/ethics/UN-declaration/

Dewey, J. (1938). Experience and cducation. New York: Collier Books.

Edmonton Public Schools – Board Policies and Regulations. (2010). Retrieved from http://policy.epsb.ca/iec.ar.shtml

Edmonton Public Schools – Specialized Programs. (n.d.). Retrieved from http://www.epsb.ca/programs/specializedprograms/

Equity. (2008). *The Organisation for Economic Co-Operation and Development.* Retrieved from http://www.oecd.org/edu/school/39989494.pdf

Equity. (n.d.). *Oxford English Dictionary*. Retrieved from http://www.oxforddictionaries.com/definition/english/equity

Fleitas, J. (2000). When Jack fell down…Jill came tumbling after: Sibling in the web of illness and disability. *The American Journal of Maternal/Child Nursing*, 255, 267-273.

Green, K. (2010). Interview by Leanne Hansen. Siblings of sick kids learn a life lesson early. On *NPR's Morning Edition*. Retrieved from http://www.npr.org/2010/11/28/131644645/siblings-of-sick-kids-learn-a-life-lesson-early

Hamama, L., Ronen, T., & Rahav, G. (2008). Self-control, self-efficacy, role overload and stress responses among siblings of children with cancer. *Healthy and Social Work,* 33(2), 121-132.

Hannon, M. (2012). supporting siblings of children with disabilities in the school setting: Implications and considerations for school counselors. *Journal of School Counseling,* 10(13).

Healthychildren.org. (2013). Siblings of children with chronic illness. *Caring for Your School-Age Child: Ages 5 to 12: American Academy of Pediatrics.* Retrieved from http://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Siblings-of-Children-with-Chronic-Ilnesses.aspx 2014

Hewitt-Taylor, J. (2009). Children who have complex health needs: Parents' experiences of their child's education. *School of Health and Social Care.* Bournemouth, Dorset, UK: Blackwell Publishing Ltd.

Hollingsworth, S. (1990). Learning to teach through collaborative conversation. A feminist approach. *American Educational Research Journal*, 28(2). 373-404.

Kirby, S. L. & McKenna, K. (1989). Experience, Research, Social Change: Methods from the Margins. Toronto: Garamond Press.

Koch-Hattem, A. (1986). Siblings' experience of pediatric cancer: Interviews with children. *Alberta Health and Social Work*, 11(2), 107-117.

Kresak, K., Gallagher, P., & Rhodes, C. (2009). Siblings of infants and toddlers with disabilities in early intervention. *Topics in Early Childhood Special Educatio,* 29(3), 143-154. doi: 10.1177/0271121409337949.

Leonard, B. (1991). Siblings of chronically ill children: A question of vulnerability versus resilience. *Pediatric Annals*, 20(9), 501-506.

Linda, G. C. (2006). Understanding families: Applying family systems theory to early childhood practice. *YC Young Children*, 61(1), 12-20.

Mama, R.S. (2010). Needs, rights, and the human family: The practicality of the convention on the rights of the child. *Child Welfare*, (5), 177.

Mertens, D. (2005). *Research and evaluation in education and psychology : Integrating diversity with quantitative, qualitative, and mixed methods*. Thousand Oaks, Calif: Sage Publications.

Nisselle, A., Green, J. & Scrimshaw, C. (2010). Transforming children's health spaces into learning places. *Health Education,* 111(2), 103-116.

Onconurse.com – Help for oncology nurses to better serve their patients. (n.d.). Siblings of children with cancer – Fact sheet. Retrieved from http://www.onconurse.com

Peshkin, A. (1988). In Search of subjectivity - One's own. *Educational Researcher*, 17(7), 17-21.

Ravindran, V. & Rempel, G. (2011). Grandparents and siblings of children with congenital heart disease. *Journal of Advanced Nursing*, 67(1), 169-175. doi: 10.111/j.1365-2648.2010.05482.x

Ray, S. (2007). Family transition experiences as perceived by caregivers of young children with spina bifida. (Doctoral Dissertation).

Resilience. (n.d.). *Oxford English Dictionary*. Retrieved from http://www.oxforddictionaries.com/definition/english/resilience

Rothstein, R. (2004). Class and schools: Using social, economic, and educational reform to close the achievement gap. *Economic Policy Institute*. Washington, 129.

Sarantakos, S. (2005). *Social research* (3rd Ed.). New York, NY: Palgrave Macmillan.

School Act. (1988). Edmonton: Government of Alberta.

Sullivan, N., Fulmer, D. & Zigmond, N. (2001). School: The normalizing factor for children with childhood leukemia: Perspectives of young survivors and their parents. *Preventing School Failure*, 46(1), 4-13.

Vanderwerp, L. (2011). Siblings and illness: A study of how children are differentially impacted by the chronic illness of a sibling. Retrieved from http://ejournals.library.vanderbilt.edu/index.php/vurj/article/viewFile/2924/1223

Wallinga, C. & Reed, M. (1990). The elementary school counselor's role with siblings of ill children. *Elementary School Guidance and Counseling*, 25(2), 91-97.

Widrick G., Whale C., DiVenere N., Vecchione E., Swartz D., & Stiffler D. (1991). The medical education project: An example of collaboration between parents and professionals. *Child Health Care*, 20, 93-100.

Wilkins, K. & Woodgate, R. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. *Journal of Pediatric Oncology Nursing*, 22, 305-319. doi: 10.1177.1043454205278035.

Wolfe, B. (1985). The influence of health on school outcomes – A multivariate approach. *Medical Care*, 23(10), 1127-1138.

Woodgate, R. (2000). Part I: An introduction to conducting qualitative research in children with cancer. *Journal of Pediatric Oncology Nursing,*17(4), 192-206. doi: 10.1053/jpon.2000.16396.

APPENDIX A: Consent and Information Document

Researcher:
Jessica Moyes
Dept of Educational Policy Studies
Faculty of Education
7-104 Education North
University of Alberta
Edmonton, AB, T6G 2G5
moyes@ualberta.ca
1(780) 965-8691

Supervisor:
Dr. Lynette Shultz
Dept of Educational Policy Studies
Faculty of Education
7-104 Education North
University of Alberta
Edmonton, AB, T6G 2G5
lshultz@ualberta.ca
1(780) 492-7625

March 15th, 2013

To Whom It May Concern:

Your family's recent stay at (the House) enables your child to participate in an exciting research opportunity that seeks to learn more about how the siblings of seriously ill children who must travel for treatment experience and make sense of their education. Jessica Moyes will carry out all research as part of a thesis study examining the educational experience of school age siblings. This study will be conducted as part of a Master of Education Policy degree in Education Leadership and Administration at the University of Alberta.

Rationale for the Study: For children, school remains the most important component of life outside the family unit and at times, unfortunate circumstances can quickly disrupt one's relationship with education. This research offers an examination of how school age siblings of seriously ill children experience education when the family unit must travel for treatment. As you know, while seriously ill school age students may attend Public School located in the hospital, the sibling students are left to find their way into the public school system or utilize the unaccredited education supports like those found at (the House). Since there are few supports aimed at educating siblings of seriously ill children and a lack of research in this field, an in-depth conversation with the sibling students and inquiry into the educational experiences of this group of students may serve to provide greater understanding.

Details of Participation: Your child's participation in this study involves interviews with Jessica Moyes. Interviews will be audio recorded and/or video recorded for later transcription. Once interviews have commenced, I will give you and your child the typed transcript. By signing this form, you are agreeing to allow your child to be audio and/or videotaped. If your child does not want to be recorded, he/she can notify me at any point and I will limit my recording to note taking. Personal artifacts may also be included in the interview process and subsequent research paper.

During the interview, your child can choose not to answer any questions he/she feels uncomfortable discussing. He/she can even stop the interview if he/she wishes. Your child's participation in this study is voluntary. Your child can choose not to participate at any point in the research process. If your child chooses to withdraw from the study, his/her information will be removed and destroyed.

Benefits of Participation: By participating in this study, your child will be able to reflect on his/her experiences at (the House) and its impact on his/her life. Your child's participation will also provide important insights into the educational experiences of siblings of seriously ill children when the family unit must travel for treatment. These are important pieces of knowledge on current education policies that affect students and in sharing this knowledge, educators and practitioners can expand their knowledge about the educational experiences of siblings of sick children.

Risks of Participating: There are no known risks to participating. Only the researcher and her advisor will be privy to your child's personal information. All raw data will be kept in confidence, stored in a locked filing cabinet and shredded after five years. Electronic data will be saved on a password protected computer and permanently erased after five years as well. (the House) will be named in the report, however no participant names will be used. Public presentations will be made on this research and results may be published, but your child's identity will remain confidential.

If you have any questions about the rights of your child as a research participant, please contact the Research Ethics Office at (780) 492-2615. If you have any further questions regarding this study or wish to receive a copy of the study results once completed, please contact: Jessica Moyes: (780) 965-8691 or moyes@ualberta.ca or Dr. Lynette Shultz: (780) 492-7625.

Sincerely,
Jessica Moyes
(780) 965-8691

Research Consent

I, the undersigned, have read and understand the above information and agree to allow my child, ___________________________, to participate in this research study outlined above.

____
Printed Name of Parent/Guardian Signature of Parent/Guardian (Date)

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615

APPENDIX B: Assent Script

Dear Student,

I, Jessica Moyes, am doing a research project for a degree at the University of Alberta. I would like to talk with you about your education experiences when you had to travel to and from home and Edmonton because your sibling required medical treatment or attention. In the conversation, we can talk about the time you spent at (the House), about the education program there and how you felt about school at that time. I would also like to record the interview so I do not have to write down all of your answers or forget anything important that you might share with me. I will erase this recording when I am finished with my research project.

During our chat, if you feel uncomfortable and do not want to answer a question for you would like to stop, you can tell me and we will stop. It is completely your choice and you do not have to worry if you want to skip questions or if you want to stop altogether. It's absolutely fine with me. And do not worry about any answers you give. There are no right or wrong answers and I will not be marking you on what you say. So now that you have heard about the interview, is it okay for me to interview you? Please say yes or no. Is it okay for me to tape record the conversation? Yes or no?

Thank you for considering this request.

Researcher:	**Supervisor:**
Jessica Moyes	Dr. Lynette Shultz
Department of Educational Policy Studies	Department of Educational Policy Studies
Faculty of Education	Faculty of Education
7-104 Education North	7-104 Education North
University of Alberta	University of Alberta
Edmonton, AB, T6G 2G5	Edmonton, AB, T6G 2G5
moyes@ualberta.ca	lshultz@ualberta.ca
1(780) 965-8691	1(780) 492-7625

APPENDIX C: Conversation Question Guide

Background
How old are you?
What grade are you in?
Where are you from?
Tell me about your family. Who stayed at (the House)?
Can you tell me why you stayed at (the House)? How many times have you stayed at (the House)?
Did/Do you anticipate going back any time soon?
When you travel for treatment for your sibling, did/does she/he mainly live in the hospital or at (the House)?
Can you describe your typical day at (the House)?

Education – General
How did/do you feel about school before your sibling got sick?
Did/Do you feelings change after your sibling got sick?
How did/do your sibling's health problems affect your school life?
Did/Do you have to move?
Did/Does it affect your attendance?
How often did/do you have to come to Edmonton for treatment for your sibling?

Alternative schooling
Tell me about school when you have to leave your home school.
Did/Do your parents teach you while you're away from home?
Did/Do you attend class at (the House)?
Did/Do you try home schooling?
How did/do each experience help you to learn? Or make it hard for you to learn?
How did/do you feel about attending school at (the House)?
How did/do the teacher teach lessons?
How was/is the schoolwork the same as the work you were given in your home school?
How was/is the schoolwork different from the work you were given in your home school?
How did/do you feel about attending school at (the House)?
What was/is your favorite part of learning at (the House)?
How did/does attending (the House) affect you? And your family?
Describe how your life changed after you enrolled in the school.
How did/does your sibling's illness interfere with your school life?
What kinds of things did/do you do around (the House) when you were not at school?
If your family didn't stay/weren't staying at (the House) and what do you think you and your parents would have done?

Home School

Tell me about your home school? Friends, teachers, etc.

Do you have a favorite class?

Did you home school teachers and classmates stay on touch with you while you were away?

How did you feel about going back to your home school? Excited? Nervous?

General

Why do you think going to school is important while your sibling was/is receiving treatment?

What do you think about going to school while living at (the House)? Was/Is it important?

If you had the chance to design a school for the siblings of sick children, what would be the most important things about this school?

Do you have anything else you would like to add?

Researcher:
Jessica Moyes
Department of Educational Policy Studies
Faculty of Education
7-104 Education North
University of Alberta
Edmonton, AB, T6G 2G5
moyes@ualberta.ca
1(780) 965-8691

Supervisor:
Dr. Lynette Shultz
Department of Educational Policy Studies
Faculty of Education
7-104 Education North
University of Alberta
Edmonton, AB, T6G 2G5
lshultz@ualberta.ca
1(780) 492-7625

APPENDIX D: Emails from Tom's Father

May 30th, 2013

Hi Jess.

Thanks for including (Tom) in your study. We think this is therapeutic in terms of his acceptance of the path we've been on, by sharing with you. He has internalized too much of what happened - especially the cardiac arrests. This scarred him, and although he learned to do the right things in the moment, he was so very scared and angry. You are probably the first person he really shared with.

(Tom's father)

October 15th, 2013

Hi Jess.

Thanks for copying the transcript for me; you have (our) approval to use it as you wish. You caught (Tom's) vernacular so perfect, and fielded some excellent questions. (He) had a few facts wrong, such as (his sister's) diagnosis date (March 2009), but you've given us a perspective on a number of things that we could not get from him ourselves. It is a help to us to better understand where he's at, and what lessons he's picked up on. In fact, I am taking my time thinking about his answers to some questions, as they surprised me. In a good way, I might add! As hard as our experiences were, so much good has come from them that we can not be sad for what transpired, and your interview proves they have influenced (Tom) positively…

Have a great fall, and please drop a note here and there. We appreciate you!

(Tom's father)

APPENDIX E: Email from Ali's Mom

July 1st, 2013

Hi Jessica,

Overall, as we recall, the most difficult obstacle was when the hospital school decided they could not let (Ali) continue to study there as the school board ruled that she as a sibling, couldn't be enrolled there. Until that time our little private school had been faxing assignments to the hospital school and the teachers there supervised it and the principal supported that until we received the board's ruling. We then switched to (House teacher) supervising but (Ali's) teachers weren't as accommodating as (Ali's sister's) teachers and (Ali's) began to fall behind. Meanwhile we had discussed (Ali's) auditioning for the (Performing Arts School) with (Ali's sister) and went ahead with the audition. She made it but the timing was bad as it was Christmas and then the end of the semester so she had to wait until the new semester began. We were required to have an (local) address to enroll in the school. It worked because we didn't know if we would move back home and might be staying in (local) as all depended on (Ali's sister's) health and the girls' choices. We feel that having two parents there was helpful for supporting and being able to be with (Ali's sister) as much as possible to advocate for her, etc, and one parent being able to drive (Ali's) to and from the school. Families with only one parent and limited funds could not do as we did. A hospital school would benefit all families.

(Ali's Mom)